Digital and face-to-face home care provision for people with long term conditions - exploring the part nutrition plays

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Digital and face-to-face home care provision for people with long term conditions – exploring the part nutrition plays

by

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Contents

Thesis Abstract

Malnutrition is the combined definition of overnutrition and undernutrition. In the UK, over 60% adults are overweight or obese and 5% are underweight. Long-term conditions are associated with malnutrition, but evidence around its management in homecare is lacking. Technological solutions to health and social care are of interest to commissioners, as technology may alleviate current constraints on staffing, resources, and budgets but robust evidence of its benefits in home care are difficult to quantify. Therefore, this thesis explores evidence of digital and face to face home care in people with long-term conditions and the current context of nutrition management in this setting.

Methods

A systematic review, meta-analysis, and narrative synthesis to compare telehealth to standard home care in people with long term conditions, and their quality of life outcomes.

An ethnographic exploration of the culture in home care provision in people with long-term conditions and the context of nutrition in this setting. In-depth focus on a small sample of clients, their carers, and the care provider to produce narratives and knowledge based on purposeful conversation, participatory observations, insight, and reflections.

Results

Systematic review:

9 studies were included in the systematic review, 2 of which were qualitative studies, reporting on a total of 2611 home care adults living with chronic condition. Meta-analyses showed telehealth was not statistically significant different to face-to-face homecare in terms of quality of life. Qualitative studies showed telehealth provided peace of mind and legitimized contact with healthcare professionals.

Ethnography:

Reflective narratives demonstrate overnutrition and undernutrition are concerns not currently addressed in CareCo Healthcare clients . Barriers to good nutrition exist from all perspectives and include constraints of

staff recruitment and training, nutrition as low priority in care planning and respect for patient autonomy. Whilst knowledgeable clients, cooking ability and advocacy facilitates good nutritional practices.

Conclusion

Much work is needed to optimise nutrition for those with long term conditions receiving home care where many complex factors come into play. The thesis discusses ways in which these complexities maybe negotiated and potential solutions reached, including those which would need to be done face to face and those which could potentially embrace telehealth.

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List of Abbreviations

ADL – Activities of Daily Living

ASC-WDS – Adult Social Care Workforce Data Set

BAPEN – British Association for Parenteral and Enteral Nutrition

BDI- Beck Depression Indicator

BDA – British Dietetic Association

BMI- Body Mass Index

DM – Diabetes Mellitus

CQC – Care Quality Commission

CHF – Chronic Heart Failure

COPD – Chronic Obstructive Pulmonary Disease

GHQ – General Health Questionnaire

GP- General Practitioner

LTC – Long Term Condition

MCS- Mental Component Score

MUST – Malnutrition Universal Screening Tool

NHS – National Health Service

NICE – National Institute of Health and Care Excellence

ONS – Office of National Statistics

PCS- Physical Component Score

PENG- Pocket Guide to Clinical Nutrition

PHE – Public Health England

PHQ 9 – Patient Health Questionnaire 9

QALY – Quality Adjusted Life Years

QuOL – Quality of Life

SDG – Sustainable Development Goal

SGRQ – St George's Respiratory Questionnaire

SING- Scottish Intercollegiate Guidelines Network

TH – Telehealth

T2DM- Type 2 Diabetes Mellitus

UK- United Kingdom

UKSSD – United Kingdom Stakeholders for Sustainable Development

List of figures and tables

Structure of this Thesis

The purpose of this thesis is to investigate the prevalence, barriers and facilitators to malnutrition in the community setting within a population of people with long term conditions who receive long term home care. This thesis explores the evidence for digital health technology in service provision and the views of those being cared for who are chronically ill. The research then moves on to explore the barriers and facilitators to nutritional wellbeing in long term conditions from the service user, carer and care provider perspective.

This thesis is comprised of six chapters.

Chapter 1 provides an introduction and overview of malnutrition in the community and is specific to the UK population of people with long term conditions. It also provides justification for the study designs used within this research (a systematic review and ethnography) to appropriately address the research questions at each phase.

Chapter 2 presents the systematic review, meta-analysis and qualitative synthesis I conducted in the early stages of my PhD, which provided a valuable insight to where nutrition stands currently within published evidence in this field. At the end of Chapter 2, I explore what the findings of the systematic review tell us and provide rationale for the next stages of my research journey.

Chapter 3 builds on the introduction to ethnography from Chapter 1 and provides detail of the study setting, participants and context. Chapter 3 details the methods section for my ethnographic study and explains the process of recruitment, data collection and analysis whilst reflecting on the interplay of power and knowledge between myself and CareCo Healthcare and how that may have framed my line of enquiry.

In Chapter 4, I present the results of my ethnographic research. Here, I include personal reflections throughout that led to simultaneous data collection and analysis during time in the field. Within this chapter, I explore positionality and reflect on my role as a research tool as well as the relationship between myself and participants. I provide reflections on my experiences and observations of care provision in the private sector compared to my career within the public care sector in the NHS.

Chapter 5 goes on to discuss how the findings fit (or not) in line with other published or available research in the field. I continue to reflect here between policy, guidelines and regulation of private versus public care sectors.

In Chapter 6, I consider the implications of my research on clinical practice and consider my results through a dietetic lens. I present the meaning this research has for healthcare services and a potential new clinical care pathway to identify malnutrition in the initial phases of care. I explore the impact this could have on patient quality of life and service provision.

1 Background

1.1 Introduction to Chapter 1

The purpose of this chapter is to provide a background to the subject area and the research methods used within my PhD. Section 1.2 is comprised of sub-sections to thoroughly introduce the topic. Section 1.3 provides rationale for undertaking a systematic review as my first step in this research project and Section 1.4 explores the rationale for undertaking ethnographic research following the systematic review, and its uses within healthcare research.

1.2 Introduction to topic

1.2.1 Malnutrition in the UK

Malnutrition can be defined as the state *of nutrition in which a deficiency or excess of energy, protein and other nutrients causes measurable adverse effects on tissue / body form (body shape, size and composition) and function and clinical outcome* (British Association of Parenteral and Enteral Nutrition (BAPEN) 2020). The definition of malnutrition refers to both undernutrition and overnutrition, and the World Health Organisation provide a definition of the double burden of malnutrition which highlights the co-existence of undernutrition in overweight and obesity with regard to micronutrient deficiency (World Health Organisation 2020). A report published in the LANCET following a series published on double burden malnutrition in December 2019, further explains the aetiology and co-existence of undernutrition in overweight and obesity with insight to health across the life-course. This report highlights important current issues around scarce epidemiological insight to dual burden malnutrition and the risk this poses to developing specific diseases, specifically non-communicable diseases. This report also highlights lack of current policy and inaction to overcome micronutrient malnutrition and dual burden malnutrition which is costly to our health services as a result (Hossain et al 2020).

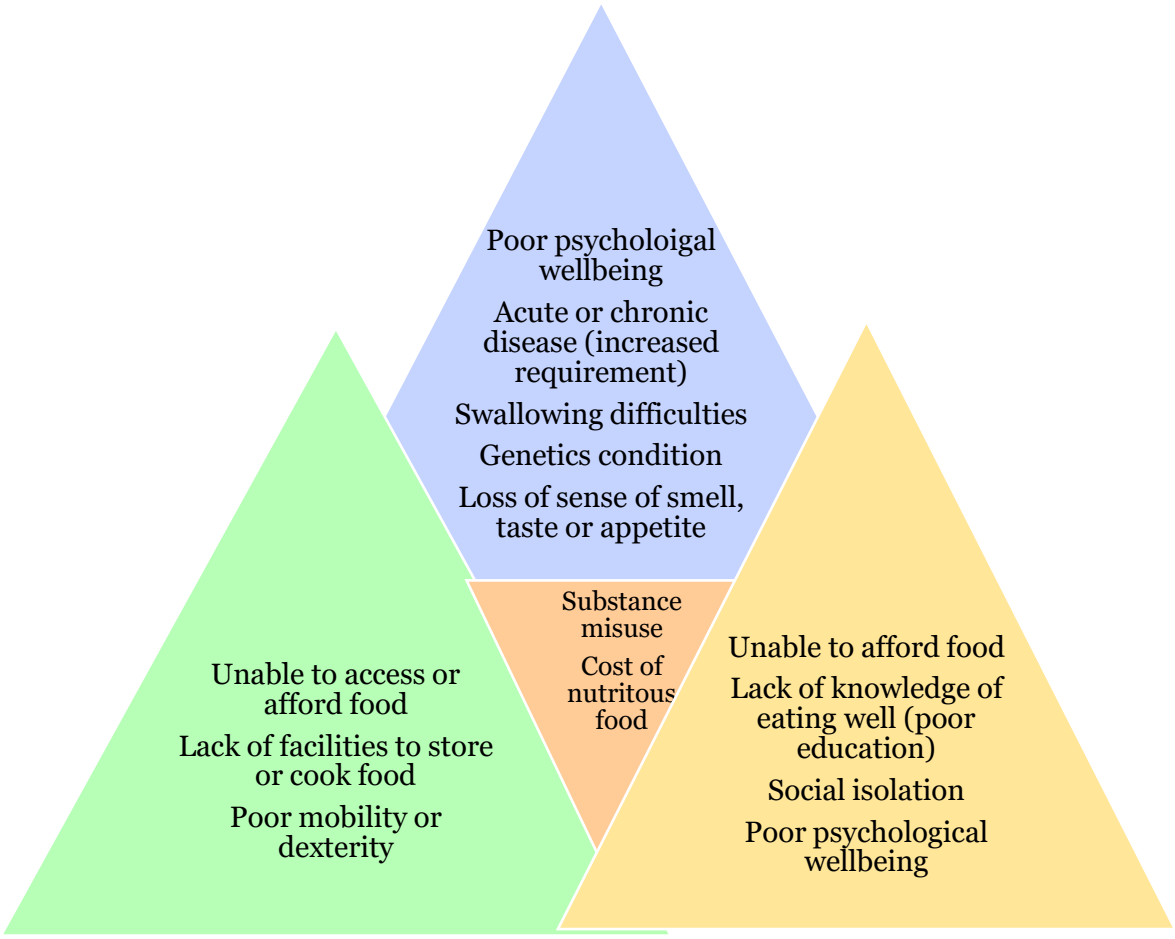
As malnutrition is more commonly documented in relation to undernutrition, for the purpose of this thesis, when I discuss malnutrition, I will be referring to undernutrition. To ensure clarity, when I discuss malnutrition with reference to excess nutrition, I will use the term overnutrition.

Malnutrition is a very common clinical and public health concern, present in all care settings, affecting people of all ages. Approximately 3 million people in the UK (5%) are malnourished (Malnutrition Pathway 2017). Meanwhile, it is estimated 30 and 34 percent of adults admitted to hospital and on hospital wards respectively, are at risk of or are malnourished and 15 percent of people attending outpatients are malnourished (BAPEN 2015). Public expenditure on malnutrition was £19.6 billion in the year 2011-12 which has increased to £23 billion by 2019 and projected to continue to increase because of an aging, more severely ill population (BAPEN 2015; Stratton, Smith and Gabe 2018).

Malnutrition within in the UK has been labelled the skeleton in the closet, awareness is growing however due to the complexity of intertwined causes, treating, or reducing malnutrition is an increasing challenge meanwhile it remains a low priority within politics. The prevalence of malnutrition is estimated more than 3 million community dwelling adults. Of which at any point in time approximately 2% and 3% are in hospital or care homes respectively, equating to approximately 95% people suffering with malnutrition living at home. Low income households are also disproportionately represented in these figures which is seldom highlighted (Elia, Russell and Stratton 2010).

The aetiology of malnutrition is complex and can derive from a range of underlying issues which I have presented below (Figure 1). I have presented common causes of malnutrition which we can identify and asses in healthcare in a figure to represent common broad categories these causes of malnutrition may be recognised within, however by no means restricted to, as many factors commonly overlap (Gandy 2019). It is important to note that malnutrition is not one-dimensional, instead it is often present due to an accumulation of issues which can change over time. For that reason, identification, assessment, and care planning should be completed sensitively and with a patient centred approach (Coulter Roberts and Dixon 2013). Not included in Figure 1 but necessary to highlight, are overarching political issues which I will go on to present.

Figure 1: Factors which can contribute or worsen malnutrition



1.2.1.1 Politics and malnutrition

The Environmental Audit Committee are a group appointed by the House of Commons, responsible for evaluating the extent to which policies and targets for national development are achievable and supported in context. A drive for action on "hunger, food insecurity and malnutrition" is Sustainable Development Goal (SDG) 2 which recognises malnutrition and food insecurity in the context of both undernutrition and overnutrition in the UK and internationally (Parliament 2019). Food insecurity is defined as "the disruption of food intake or eating patterns because of lack of money and other resources" which does not always cause undernutrition or hunger but can be a contributing factor (Office for Disease Prevention and Health Promotion

2020). In 2018 UK Stakeholders for Sustainable Development (UKSSD) conducted and published a "Measuring Up" report which evaluated UK performance and progress in achieving SDG's. That report was the first of its kind and found "while there is an enormous amount to celebrate, the most vulnerable people and places in our society are increasingly being left behind" (UKSSD 2018).

When we consider why this is the case, specifically with SDG 2: Hunger, food insecurity and malnutrition, it is important to consider 5 of the targets within this goal considered relevant to the UK context. Three targets relate to improving food production systems, agricultural productivity, and genetic diversity of seeds. Of these, the UKSSD identify gaps in policy coverage in these areas, below adequate or deteriorating performance in the UK (presented as amber rating on the scale). This lack of policy, poor or deteriorating performance to action targets also applies for the target to end hunger (undernutrition) by 2030 and ensure sufficient, nutritious food is accessible for all, all year, particularly vulnerable or poor populations. The fifth target under SDG 2 assessed by UKSSD aims to 'end all forms of malnutrition' (here relating to undernutrition and overnutrition) by 2030 and 'address the nutritional needs' of children, 'pregnant and lactating women and older persons.' This is the only target rated red. Red indicates "There is little or no policy in place to adequately address the target" (Parliament 2019). The juxtaposition of malnutrition when considering a UK average conceals the political, socioeconomic, and environmental challenges for the UK to tackle undernutrition and overnutrition. This report, however, highlights that undernutrition and overnutrition remain significant issues in the UK and a reason for that, likely relates to lack of policy driven action.

Findings from these recent reports highlight that also a national agenda is set, in the UK we still have a way to go to ensure goals are met through filling the gaps in current policy and developing new policy to drive change. Without which, the disparity between the health status within our nation will continue to grow (UKSSD 2018). This is evidenced by increasing levels of overweight (63% adults) and obesity (27% adults) and diet-related ill-health (British Medical Association 2018). Meanwhile, the level of food insecurity continues to increase, as demonstrated by a cross-sectional Food and You Survey (2016) which recruited a representative sample of adults (16 years and over) (n=3118) living in the England, Wales and Northern Ireland to examine characteristics associated with food insecurity. The cross-sectional study adopted the US Department of Agriculture 10-item Adult Food Security tool which has been validated for use of assessing

food insecurity in economically developed countries (Loopstra, Reeves and Tatasuk 2019). This data was analysed and compared to the findings of the 2004 Low Income Diet and Nutrition Survey (which was conducted for all the UK including Scotland). It is important to mention that this data is relatively old now and food poverty has risen almost exponentially in that time. This is evidenced by latest figures that 1,900,122 people utilized foodbanks in 2019/20 compared to 913, 982 in 2013/14 (The Trussell Trust 2020). Neither survey was designed to be compared and so respondents from Scotland were excluded to allow results to be comparable which may have influenced the overall effect reported and introduced selection bias to the sample. However, multivariate analysis was conducted, and conclusions were drawn that the probability of adults from low-income households experiencing food insecurity had risen from 27.7% to 45.8% from 2004 to 2016 respectively. A key finding from that research which is relative to this thesis is that people with long-term conditions which were particularly debilitating in relation to ability to carry out activities of daily life or diagnosis of a disability were strongly related to food insecurity, despite adjusting for economic income (Loopstra, Reeves and Tatasuk 2019).

1.2.1.2 Evidence of malnutrition and adverse effects

Malnutrition is such a substantial issue within health and social care because of its direct correlation with increased risk of infection, falls and hospital admissions, poorer wound healing, and recovery (meaning longer hospital stays or rehabilitation in the community). Malnutrition is also linked to lower mood, reduced ability to independently care out activities of daily life and poorer quality of life a range, hence increased awareness and work to identify those at risk or with nutritional needs is required (British Dietetic Association (BDA) 2020).

Rasheed and Woods (2013) conducted a systematic review and meta-analysis of nutritional status and clinical outcomes of older adults in rehabilitation included 3903 participants from 14 observational studies and 16 intervention trials (clear documentation of concealed randomisation, blinding, or intention to treat analysis was seldom reported). Papers included were of English language only which reported on adults aged 65 or over. Intervention studies which measured quality of life before or after nutritional intervention or compared

to a control cohort were included. Observational studies which compared quality of life in malnourished adults to controls were also included. Only studies which used validated tools for assessing quality of life were included. Heterogeneity was significant in terms of how included studies assessed for malnutrition or nutritional requirements were estimated. 13 trials which compared nutritional intervention to routine care saw statistically significant improvement in physical quality of life in the intervention group ($p<0.002$). Data from 9 trials which reported on psychological wellbeing show favoured nutritional support for improvement in the mental component of quality- of life on EQ5D ($p<0.001$) (Rasheed and Woods 2012).

Given the complexity of interweaving, overlapping issues which relate to nutrition, health, and wellbeing it is not accurate to state a causal effect. Rather, that these finding are suggestive nutritional assessment and supervision can be beneficial to various aspects of quality of life in the participants studied and that nutrition is a proxy for these various factors contributing to quality of life.

Overall rates of mortality have been statistically significantly linked ($p<0.03$) to patients who scored more highly on Malnutrition Universal Screening Tool (MUST) to acute care (Stratton et al 2006). This prospective study consecutively recruited 150 elderly patients (aged years 85 SD 5.5) who had emergent admissions to hospital and an experienced dietitian screened them upon admission using MUST. Reasons for admission included falls, cardiac and respiratory disease, cerebrovascular accident renal failure and gastrointestinal disorders. Malnutrition was prevalent in 58 percent (n=87) people, with 17 percent (n=25) and 41 percent (n=62) scoring medium and high risk respectively. In those who left hospital (n=119) mortality rates were significantly greater in those assessed as medium and high risk of malnutrition at 3- and 6-months post discharge at 12 percent (n=14) and 21 percent (n=25) respectively. Patients who were not able to be weighed to complete MUST objectively were 70 percent higher risk of malnutrition. In 35 patients whom provided subjective detail to complete MUST, a significant increase in risk of malnutrition was noted, alongside longer length of stay ($p< 0.0005$), requiring discharge somewhere other than home ($p <0.0005$) and higher rates of inpatient mortality ($p< 0.02$) (Stratton et al 2006). Despite the methodological approach of this study, results should be interpreted with caution as the impact of disease severity or underlying conditions is not documented. As with the results of Rasheed and Woods (2012) results should be interpreted as a suggestion of the influence undernutrition can play in clinical outcomes, rather than assuming cause and effect.

Anthropometry in patients being treated for neuroendocrine neoplasia found malnutrition was associated with longer hospital stays and reduced long term survival rates (Maasberg 2017). Another prospective study of an older adult rehabilitation ward recruited 133 adults, 63 of whom were at risk of malnutrition and eight of whom were malnourished upon admission. Results from prospective study reflect those of Maasberg 2017 in that subjects at risk of malnutrition/malnourished had longer length of stay ($p < 0.023$) and were more likely to be admitted to higher level care ($p < 0.05$). Malnourished subjects also had poorer function on admission ($p < 0.001$) and at 90 days follow up. ($p <0.002$). Quality of life was poorer in those at risk of malnutrition or malnourished both on admission ($P < 0.008$) and at 90 days ($P < 0.001$). The 8 malnourished subjects and those with low corrected arm muscle area (CAMA) were twice as likely to be admitted for higher level care ($P < 0.05$) and also had poorer functional outcomes at 90 day follow up ($P < 0.017$) (Rasheed and Woods 2013).

These recent studies identify malnutrition is a prevalent issue and that increased priority to prevent, identify and treat malnutrition within politics, health and social care should be a matter of importance and urgency as there is growing evidence of its association with adverse effects and poorer quality of life.

1.2.2 Long term conditions the UK

A long-term condition has been defined as “a condition that cannot, at present be cured; but can be controlled by medication and other therapies” (Department of Health 2010). Examples provided of these sorts of conditions include cardiovascular disease, pulmonary disease and diabetes.

In the United Kingdom (UK), there are 26 million adults living with a long-term condition, 10 million have a diagnosis of two long term conditions (NHS England 2018). According to the report from the Office of National Statistics (ONS) 2012, the over 65 population is projected to increase by 49% from 9.7 million to 14.5 million between 2015 and 2035 (Wittenberg and Hu 2015). The concern of this aging population with poorer quality of life is the projected increase of 74 percent in people who are unable to perform at least one activity of daily living (ADL) and therefore requiring home care services. This is an estimated growth from

1.15 million people to 2 million people by 2035, a rate at which homecare providers are already struggling to meet (Wittenberg and Hu 2015).

Services and care provision for people with long term conditions now accounts for 70 percent of the annual health and social care spend (Department of Health and Social Care 2015). This population group utilise 50 per cent of all GP appointments, 64 per cent of all outpatient appointments and in excess of 70 per cent all inpatient bed days (The Kings Fund 2018). In addition to human cost, the financial cost associated with this equates to an additional £5billion annual spend of the total healthcare budget (The Kings Fund 2018). By 2020-21, a £30 billion funding gap is forecast in health and social care as a result of long-term conditions, together with an aging population, in the UK [4, 6]. This healthcare burden is outstripping healthcare resources and community provision and at present, £7 in every £10 of public health and social care expenditure, is spent on managing long-term conditions (The Richmond Group of Charities 2015).
Living with a chronic condition can have vast and detrimental impacts on a person's life. Ability to work, travel and have relationships are just some of those areas. Education, employment and housing could be impacted as consequence of poor health (Public Health England 2014). These challenges are heightened by population growth meaning increased need, at a time of funding cuts and staff shortages as well as the typical 'time and task' model of home care services. Time and task model remains the predominant model for commissioning home care whereby visits are commissioned to be delivered in short time slots (15-30minutes) and focus on personal care tasks (Jefferson et al 2018). Hence, this multi-faceted, complex and high-risk population group is one worth researching in order to drive sustainable improvements for care provision.

Sarcopenia is a condition characterised by depletion of skeletal muscle, in terms of both strength and mass which positively corelates with poor quality of life, physical disability and mortality. Given the adverse effects of this long term condition in terms of activities of daily life and the eventual reliance on care support, sarcopenia is one example of a very real concern and challenge in a growing population, and how care needs are met. More recently, sarcopenic obesity has been highlighted particularly in older adults whereby more overweight and obese adults are being identified as suffering from sarcopenia (Wannamethee and Atkins 2015). In the context of co-morbidity, sarcopenia and sarcopenic obesity corelate to diagnosis and adverse

outcomes in adults with cardiovascular disease and its associated risk factors (Wannamethee and Atkins 2015).

This year (2020) the Chief Medical Officers for England, Scotland, Wales and Northern Ireland and medical directors published an editorial which presents current challenges to the health and social care sectors in dealing with the rise of multimorbidity in the UK (Whitty et al 2020). One key message from that paper is the need to treat multimorbidity and disease clusters. For example, diabetologists who provide care and treatment for multiorgan diseases associated to diabetes such as renal, cardiology, neuroendocrine, podiatry and ophthalmology. The Chief Medical Officers recognise in this paper that despite the inevitability of multimorbidity dominating future care, our health system at present is not designed to treat patients in this way. This publication is a call for action in medical training, guideline development and the UK Government agenda. It identifies the need work in collaboration with the medical and allied health professional workforce to drive multidisciplinary, holistic care to respond effectively to the growing level of multi-morbidity (Whitty et al 2020).

The Richmond Group of Charities is a UK organisation which consists of 14 leading voluntary health and social care organisations including British Red Cross, Age UK, Diabetes UK, British Lung Foundation and Rethink Mental Illness, to name a few. The Richmond Group of Charities published an Executive Report on multi-morbidity to raise the profile of one of the most burdensome, multifaceted challenges facing our current and future health and social care system. This comprehensive report outlines our fragmented health and social care systems. This supports the point raised by Chief Medical Officers this year that work is needed from a political and systematic level to ensure care and training is conducive for professionals to deal with disease clusters rather than diseases as individual and separate (Aiden 2018). Both reports make known the social determinants of health and correlation between socio-economic deprivation and multimorbidity (Aiden 2018, Whitty et al 2020). For that reason, consideration should be taken for non-medical management of multi-morbidity (for example, social prescribing) to provide longer term holistic care which may improve quality of life and reduce cost of medical management (Aiden 2018). Nutrition was not specifically focussed on

throughout this report, but it was implied through holistic, non-medical management of multimorbidity. The context of worsening multi-morbidity is cause for nutritional concern which I explore in the next section of this chapter.

1.2.3 Context of undernutrition and inequalities in people with long term conditions

Social determinants of health and wellbeing are key to highlight when introducing the correlation between disease prevalence and malnutrition. Social determinants of health relate to the wider contributing factors to health, health behaviour and years living in good health which consist of social, economic and environmental constituents (Public Health England 2018). Evidence of strong correlation between diagnosis of long-term condition, illness burden and lower socio-economic status has been long standing (Steel et al 2014; The Kings Fund 2020; Singer et al 2019). People living in poverty and lower socio-economic status are more likely to have poor health, a higher number of chronic diseases and less likely to access services despite care being free at the point of access for all in the UK (Steel et al 2014). Living in poorer wealth and health can predispose and worsen risk of malnutrition if someone is unable to access, afford or prepare nutritional food.

An investigation by The Kings Fund was published this year and found 50 percent of people with long-term conditions considered their condition as a key barrier to the type or amount of work they are able to do. This statistic increased to 80 percent in people who had three or more long term conditions (The Kings Fund 2020). This demonstrates aside from the direct physical and mental impact of a long-term condition on the health of an individuals, there are indirect consequences of chronic illness which include employment . Financial implications of feeling of being less able to engage in employment and for as long as one would like to need to be considered with regards to access and affordability of food, along with the psychological implications which may follow.

In relation to direct impact of disease and malnutrition, the combination of experiencing acute disease, polypharmacy and underlying chronic illness often result in lack of interest in food, disturbed appetite, low energy, or motivation to prepare or eat or drink adequately. This predisposes already vulnerable, chronically

ill adults to malnutrition. Opinion amongst general practitioners is that, the population group with multiple morbidities is projected to increase, anticipating that may too, cause the prevalence and severity of malnutrition to increase (Nathan 2020).

This population is such high risk due to risks of malnutrition being a double-edged sword. On one hand we consider the reduction in appetite, intake or ability to eat and drink adequately in those chronically unwell. Meanwhile long-term conditions alter and often increase nutritional requirements, meaning there is larger need to bridge the gap between intake and
requirements (Todorovic & Micklewright 2011). This can often lead to weight loss, reduced strength or functional ability which can reduce independent or ability to complete activities of daily life (ADL's) further reducing the likelihood of meeting someone's nutritional requirements. For example, COPD patients have an increased energy requirement of 15-20 percent higher than their disease-free counterparts (Todorovic & Micklewright 2011). This is due to the increased energy required for the body to function normally. Alongside increased requirements, my clinical experience saw disease progression of COPD led to more severe breathing difficulties, reduced ability to walk to the shops to buy food or carry bags of food shopping home. Once people had access to food at home, they were less able to stand to prepare food, chew and swallow normal textured diet and finish full portions is reduced. Therefore, weight loss and loss of muscle strength in this patient group is rife as people are unable to meet their increased nutritional requirements due to a broad range of factors of physical, social and emotional factors. Unintentional weight loss and low BMI then poses increased risk of contracting a chest infection, longer recovery time, and unplanned readmission.

1.2.4 Context of overnutrition in people with long term conditions

As with malnutrition, prevalence of overnutrition and obesity have been linked to social determinants of health. Income, lower socioeconomic status and ethnicity have all been identified as factors increasing the likelihood of obesity (Marmot 2010). The Foresight report acknowledges that despite food intake being perceived as individual choice and responsibility to maintain energy balance, we are influenced by our food environment, indicating wider political underpinnings. The increased availability, affordability and

accessibility of energy-dense fast food now makes it more difficult to sustain healthier lives (Butland et al 2007). To add, Public Health England estimated in 2014 that in the UK there are now over 50,000 fast food and takeaway outlets (which is likely to have increased since that time) and there are five times more outlets in more deprived communities (Public Health England 2017).

Overnutrition occurs when energy consumption exceeds energy required which leads to its storage as fat within the body. Overweight and obesity are defined as "abnormal or excessive fat accumulation that presents a risk to health" (World Health Organisation (WHO) 2020). Crude measures of body mass categorise weight categories and overweight and obesity guidelines were published in Clinical Guideline CG189 by NICE (NICE 2014). That guideline states we should consider "healthy weight" as BMI 18.5-24.9kg/m², "overweight" as BMI 25-29.9kg/m², "obese I" as BMI 30-34.9 over kg/m², obese I1" as BMI 35-39.9 over kg/m² and "obese II" as BMI 40kg/m² or over (NICE 2014). Obesity has been labelled a chronic disease however support of this label is controversial (Wilding, Mooney and Pile 2019 and Eggar and Dixon 2009). I feel that it has a place being labelled as a chronic disease due to its complex aetiology and chronic existence in most patients.

The official statistics on Obesity, Physical Activity and Diet, England (2020) reported increasing prevalence of adult overweight and obesity. A majority of adults in the UK are now overweight or obese and of those and prevalence is higher in males, 67 and 60 percent males and females respectively (NHS Digital 2020). Overweight and obesity is of fundamental concern within health and social care, policy, and research. It is associated with mortality, onset of diabetes, cardiovascular disease, cerebrovascular disease, and some cancers, mental illness (such as depression) and poorer physical function (WHO 2020; Centres for Disease Control and Prevention 2020). In particular, central obesity (abdominal adiposity) measured by BMI and waist circumference (in centimetres) are risk factors for type 2 diabetes and cardiovascular disease (Scottish Intercollegiate Guidelines Network (SIGN) 2010).

In 2007, analyses were published from the annual Health Surveys for England (which are nationally representative cross-sectional surveys) on adults aged 35 years from 1993 to 2003. On consecutive years, weight, height, waist circumference, medical history, and blood pressure readings. Validated methods were used (for example, a nurse took three readings of waist circumference and the average of the second and last

reading was documented). Regression analysis was used to adjust for age, smoking, alcohol consumption, socioeconomic status and physical activity. Results showed generalised obesity (categorised as BMI>30kg/m²) increased by 11 percent and 6 percent in males and females respectively, between 1993 and 2003. Abdominal obesity increased by 13 percent (26 to 39 percent) and 14 percent (32 to 47 percent) in males and females. Generalised and abdominal obesity were both significantly associated with diagnosis of hypertension, type 2 diabetes and hypertension diabetes co-morbidity (HDC) even after adjusting for the confounders listed above. As generalised obesity increased, odds of HDC increased from 1.14, 2.56 and 2.62 in men and 2.10, 2.06 and 3.02 at 1994, 1998 and 2003 respectively (Hirani, Zaninotto and Primatesta 2007). In this study, nutritional intake was not assessed and no nutrient composition owing to disease manifestation was possible to confidently state. However, given these results still stand having adjusted for physical activity level (which would allow for energy expenditure) and alcohol intake (which would constitute additional calories consumed), it is reasonable to conclude that overall overnutrition leads to weight gain and can be associated with co-morbidities such as hypertension and diabetes.

SIGN (2010) clinical guideline recommend nutritional assessment and care plan to encourage 5-10 percent weight loss for managing overweight and obesity because of the range of health benefits associated. The benefits of achieving and maintaining this level of weight loss are far reaching. Improved lipid profiles, reduced osteoarthritis related disability, reduced all cause, cancer and diabetes mortality, reduced blood pressure, better regulated glycaemic control and reduced risk of type II diabetes as well as improved lung function in asthma patients (SIGN 2010). This presents how beneficial addressing overnutrition can be for patient quality of life as well as reducing risks of developing or worsening long term condition outcomes.

Alongside pre-disposing people to developing long-term conditions, being overweight or obese can cause adverse effects and additional challenges when treating people with chronic illness. Being obese with co-morbidities is associated with lower life expectancy, poorer mobility, mental health and quality of life (Department of Health and Social Care 2020). This can be partly attributed to diet-related ill health.

The cost of overnutrition, overweight and obesity is estimated at £6.1 billion, and the wider context and indirect cost of obesity to the NHS and society has been estimated at £27 billion (Public Health England 2017). To put this into financial and societal context, public expenditure to treat obesity and diabetes exceeds

public expenditure on the police and fire services and judicial system combined (Public Health England 2017). It is therefore of individual, societal and political interest to address overnutrition in the UK to improve health outcomes meanwhile working to reduce the financial burden on our health and social care system.

Strategies to combat obesity have been implemented for years, with targets to pledges made to improve the food environment, to encourage eating fewer calories and slow the rate of obesity growth (Department of Health and Social Care 2015). However, since
Coronavirus 19 there is even greater significant public interest to tackle obesity, given the documented adverse outcomes associated (overall mortality, likelihood of higher level of care required) and it is likely this national agenda spotlight on overnutrition will continue (Department of Health and Social Care 2020).

It is interesting to note here how overweight and obesity have been of higher interest and priority within public health and policy in comparison to the little action so far to address malnutrition. Nonetheless, the impact on quality of life of those who are living with long term conditions and at risk of malnutrition, malnourished or over nourished is significant. When we consider this with the burden on services, public expenditure, and staffing, it is of no doubt there is scope for improvement. Research and improvement work in this area has the potential to produce benefit as an individual, community, population and national level.

1.2.5 Long term conditions and psychological wellbeing

Twenty-six million people in the UK are living with one long-term condition (LTC) and the number of people living with three or more long-term conditions is rising. Those living with a long-term condition are 2-3 times more likely to have poor mental health, in particular depression and anxiety, than the rest of the population. Chronic obstructive pulmonary disease is associated with a three times greater prevalence of a mental health condition and those with cardiovascular disease or diabetes mellitus have a 2-3-fold higher prevalence of depression than those without these diseases (National Institute for health and Care Excellence (NICE) 2009; The Kings Fund (2012). For service provision, there is a 45-75 percent higher cost associated with treating

patients with one or more long term physical health condition with a mental health co-morbidity (Aiden 2018).

A causal relationship between diagnosis of a physical long-term condition and development of poor psychological relationship has not been confirmed, only suggested. Meanwhile, evidence exists which suggests a relationship between poor psychological wellbeing (depression) at baseline and poorer outcomes or self-management of long-term illness at follow up.

An example is the Rancho Bernardo Heart and Chronic Disease Study which was a prospective study carried out in California, in Caucasian adults aged 50-89 years. 2375 adults were recruited into the original cohort, and 1180 surviving members were reassessed 8 years later. At both visits, height (in metres), weight (in kilograms) were measured to calculate BMI. The Beck Depression Inventory (BDI) was used to assess depressive symptoms but excluded three items (guilt expectation of punishment and self-hate) to reduce effort of completing the tool without jeopardising validity within this population. Fasting plasma glucose and non-fasting plasma glucose readings were documented, along with if patients had already been diagnosed by a clinician with type 2 diabetes or were taking medication for blood glucose control. The average age of participants was 66.2 (standard deviation (S.D) 8.7). After adjusting for age and physical activity, mean scores had increased on the depression scale (indicating poorer mental health) ($p<0.001$), mean levels of non-fasting blood glucose had increased compared to baseline ($p<0001$) and an increased prevalence of type 2 diabetes ($p<0.001$) at 8 years follow up was noted (Palinkas, Lee and Barrett-Connor 2004). Results of this study do not demonstrate causal relationship, nor clinical diagnoses of depression. However, the results of 8 year follow up in this participant group imply an association between physical long-term illness and poorer mental wellbeing. This is important to be aware of and be mindful of throughout my thesis as nutritional intake has a role to play in both physical and mental wellbeing as I have previously discussed.

This is meanwhile symptoms of their condition, augmented by reduced psychological wellbeing and/or side effects of medications, or attempts to self-medicate can worsen appetite and nutritional intake (British Specialist Nutrition Association 2013).

1.2.6 Current management strategies to identify malnutrition in the community

Dietitians are registered and regulated healthcare professionals who are qualified to assess, diagnose and treat dietary problems on an individual basis and at a public health level. The role of a dietitian is to complete nutritional assessments, diagnoses and devise treatment plans using up to date scientific research and best practice guidelines to empower individuals and populations to make informed food choices to improve nutritional status, health and wellbeing.

Diet and obesity are main factors in many chronic conditions so timely and effective nutritional intervention is an essential aspect of overall disease management to optimise clinical outcomes such as quality of life and prevent hospital admission (BDA 2019).

Nutrition support is a key part of dietitian's role to prevent admission to hospital and improve recovery and rehabilitation. Oral nutritional supplements are essential for many patients to optimise dietary intake and nutritional status. Beck, Holst and Rasmussen completed a systematic review and meta-analysis on the use of oral nutritional support in over 65 year olds after discharge from hospital. This systematic review comprised data from 6 studies, 3 of which were Cochrane reviews, and 716 randomly allocated participants, comparing oral nutrition support in the form of oral nutritional supplements compared to a placebo or standard care. Positive effects on nutritional intake and nutritional status (secondary outcomes) were found in all studies, measured by energy and protein intake, weight or BMI, one study also found positive effect on hand grip strength however the general impact was limited. Three of the included studies reported compliance of nutrition intervention which varied from 38% to 67%, and 2 studies reported gastrointestinal disturbances. However, no significant effects were found on mortality (odds ratio 0.80 (95% confidence interval (CI) 0.46 to 1.39) or readmission to hospital (odds ratio 1.07 (95% CI 0.71 to 1.61). The drop-out rate of participants was up to 44%, particularly seen in medical patients and the rate of readmission was up to 56% which seems high however given the nature of participants being studied, these rates are not surprising. Despite no significant findings in terms of mortality and readmission, this systematic review highlights the use of oral nutritional supplements and dietary optimisation. These results present the need for more research in the field of nutrition and rehabilitation in this context and exploration of effective interventions and methods to

improve compliance within patient groups to optimise nutritional status and reduce risk of mortality and readmission (Beck, Holst and Rasmussen 2012).

One key strategy to identify and treat malnutrition or those at risk of malnutrition is through nutritional screening. Nutritional screening is a process devised by dietitians for the use of healthcare professionals and carers through a process of training and education and is now recognised as a universal tool within healthcare practice (British Dietetic Association 2020).

In 2003, a BAPEN committee (Malnutrition Advisory Group) developed the Malnutrition Universal Screening Tool (MUST) as a universal screening tool to identify malnutrition in care home, community, and hospital dwelling adults. This tool remains supported and advocated by both governmental and non-governmental bodies which include the British Dietetic Association and the Royal College of Nursing (BAPEN 2020). The tool consists of five steps, the first 3 steps are scored 0-2 which correlate to severity:

1) Measure height (in metres) and weight (in kilograms) to calculate body mass index (BMI) in kilograms per metres squared. If standard measures of height or weight or unattainable, the tool provides alternate methods to measure.

   MUST score: BMI > 20kg/m² = 0, BMI 18.5-20kg/m²= 1, BMI < 18.5kg/m² = 2
2) Document unintentional (percentage) weight loss

   MUST score: <5% =0, 5-10% =1, >10% = 2
3) Establish acute disease effect (unlikely to apply outside of hospital)

   MUST score =2 if acutely unwell and no/little nutritional intake for over 5 days
4) Add scores from step 1, 2 and 3 to obtain overall risk of malnutrition
5) Follow management guidelines/ local care policy to develop and implement a care plan

The use of MUST is now advocated by NICE guideline in their Quality Standard for Nutritional Support in Adults (BAPEN 2020; NICE 2020). Its use as a quick method of screening with clear pathways for use and implementing care have been well acknowledged and it is now used in many other European countries and others around the world (BAPEN 2016).

MUST is recognised nationally and internationally as a quick, valid and reliable method of nutritional screening, promoting multidisciplinary responsible for identifying malnutrition which can lead to improvement in clinical outcomes (BAPEN 2020). However, MUST is not without limitations. A significant limitation in relation to this thesis is that MUST does not account for chronic illness, such as sarcopenia or emotional dimensions of long-term conditions which, as outlined earlier in the chapter can have a significant impact on risk of malnutrition and double burden malnutrition (Tuner and Kelly 2000). In terms of clinical outcomes, there is a very real concern of overlooking "hidden" health problems" which can be detrimental to nutritional status and quality of life. The use nutritional screening to assess for risk of malnutrition and double burden malnutrition is discussed and explored in Chapter 4, 5 and 6.

The NHS Outcomes Framework was launched by the Department of Health and Social Care between 2010-2012 to identify and monitor specific outcomes of concern for the welfare of adults and children in England (NHS Digital 2019). Enhancing the quality of life for people with long-term conditions has remained on this agenda since it started however specific priority on nutritional wellbeing as an aspect of quality of life is lacking.

1.2.7 Home care setting

Home healthcare, also known as domiciliary care, aims to support people with long term and life-limiting conditions to remain living in their own homes and prevent (recurrent) hospital admissions (The Kings Fund 2018). Services include personal hygiene, helping people out of bed and meal preparation, yet the Department of Health report two thirds of local authorities in the UK have reduced their funding in this area (Age UK 2014). The independent sector is responsible for providing 89 percent of home care services in the UK which equates to £1.9billion public expenditure (Care Quality Commission 2019).

In 2015, there were over 350,000 older adults receiving home care, meanwhile a further 76,300 adults and younger people were receiving home care support for learning or physical disability or mental health problems (Wittenberg and Hu 2015). Given the projections for population increase requiring support, it is

concerning that there is an annual shortage of staff recruited into domiciliary care roles of over 110,000 vacancies at any one time (The Kings Fund 2018).

Commissioning of home care services has traditionally been on a 'time to task' model. This model works to prioritise the number of people seen in a particular time frame, overlooking the quality of care to meet needs on an individual basis (National Institute for Health and Care Excellence (NICE) 2015). The general consensus when we think of home care initially is for us to assume this model however this is not what I am referring to in this thesis.

Throughout this thesis, home care instead is referring to continuing healthcare which is elsewhere defined as "Care provided over an extended period of time to a person aged 18 or over, to meet physical or mental health needs which have arisen as a result of disability, accident or illness." This type of care draws on health and social care from the NHS and private providers and can be provided in a range of settings, the access to which services is dependent on the assessed needs of the individual (reference anonymised).

Packages of care for long term home care or continuing care are devised through thorough assessment and have to consider high quality care, services and resources available locally to the patient, patient preferences and importantly financial obligation. For these reasons, although patient choice is one aspect, if they wish to remain residing in their own home, it is not an automatic right for this to be funded (reference anonymised).

1.2.8 Digital health technologies

Technological innovations to replace or aid the existing workforce in community health have been of more recent interest, with technology being recognised as a necessity for the future of healthcare in the NHS Five Year Forward View (NHS England 2014). This was built on by the Kings Fund, who released a publication in 2016 presenting "The Digital Revolution: 8 Technologies that will revolutionise healthcare" which reported on use of smartphones, apps, and connected communities – to name a few (The Kings Fund 2016).

In 2011, the Department of Health reported use of telehealth can reduce mortality, accident and emergency visits and emergency admissions by 45%, 15% and 20% respectively (Department of Health 2011). This was later contrasted by a population-specific randomised controlled trial that showed telehealth is not cost-effective in people with diabetes, heart failure and chronic obstructive pulmonary disease (COPD) to benefit quality of life (Whole Systems Demonstrator trial).

Several examples of technology enabled home care have been implemented in the past with varying levels of impact in terms of quality of life, hospital admissions and cost-benefit (Beale et al 2010; National Disability Authority 2018). However, widespread adoption and uptake of telehealth is poor among all stakeholders; this includes service users, carers, healthcare professionals and commissioners (The Kings Fund 2018). From a professional point of view, this may be due to the heterogeneity of evidence; meaning effectiveness is unclear and perceived beliefs around additional work burden at an already stretched and high-pressure time (Clark and Goodwin 2010). From a service-user point of view, telehealth may be an unwelcome and constant reminder of having a chronic condition. Service users may like the taking daily medical readings or having medical technology in their home (McDowell et al 2014). The older population may be insufficiently well acquainted with technology to embrace its use. They may be concerned telehealth will impact negatively on their current treatment and undermine valued healthcare services and relationships with healthcare professionals (Sanders et al 2012; Gale and Sultan 2012; Gorst, Coates and Armitage 2015). Although research suggests that the baby boomer generation, i.e. those aged 60 – 75years are the highest users of Facebook which may mean there are opportunities for the future.

A recent publication from The Kings Fund outlines the key areas of focus so far for digital health technologies; pressure sore prevention, tackling social isolation and falls prevention (Carretero 2015, Mountain 2014, Voluntary Organisations Disability Group and The National Care Forum 2013 cited in The Kings Fund 2018). The review is inclusive of a wide range of implemented technologies in terms of remote monitoring, telecare, telehealth, sensor devices and assistive technologies. It is interesting to note here that despite malnutrition being well documented as a key challenge in long-term condition, community dwelling adults, no technology solutions toward this have been reported (The Kings Fund 2018).

In my background reading I initially searched for studies which compared telehealth to standard face to face home care with nutrition as an outcome. I did a scoping search of MEDLINE and Cumulative Index to Nursing and Allied Health Literature (CINAHL). I used MeSH terms and key words to conduct my initial search. These terms included *telehealth, telemedicine, telemonitoring, telepractice, telenursing, telecare, ehealth, e-health, mhealth or digital health or technology.* I used Boolean operator "and" to search for these terms in relation to nutrition and used terms *nutrition or diet or food or nourishment or food intake or eating.* I also search for evidence on telehealth (and its constituents) with the Boolean operator "and" to search for *weight* or *BMI or hand grip strength or skinfold.* From this scoping search it became clear that no studies had been published which compared the use of telehealth to standard home care in people chronic illness or long-term conditions with nutrition as an outcome. For that reason, I went on to do a formal systematic review of telehealth in a broader context to explore whether it is beneficial to people's quality of life who have long term conditions, in comparison to standard home care.

1.2.9 Summary of rationale for my PhD

From the research presented in 1.2, it is clear that, despite there being a growing body of research into malnutrition in the community and it being a known epidemic, concise, constructive evidence around how to manage it in terms of identification, assessment, treatment and prevention are lacking.

This is also despite long standing reports of the association between malnutrition and poorer clinical outcomes, increased number of hospital admissions, increased bed days of care, longer recovery times, increased risk of infection and higher mortality rates. The issue is augmented by increased barriers due to poorer psychological wellbeing. We know that there is a huge population at great risk of and suffering from malnutrition, however, there is very little published evidence that considers malnutrition as a significant primary outcome.

Meanwhile, we have a society that is driving towards being more technologically focussed and moving toward a healthcare system which aims to optimise service efficiency through replacement or practical replacement of

human interaction which technology as its main interface. This is without having context specific evidence of what works, in which population groups and specifically in age groups.

For that reason, in order to work toward improving this current epidemic and how best to manage it to improve the quality of life of millions of people, we need to understand the evidence that currently exists in this context and analyse it in detail. Based on those results, it is then necessary to go into the field and work alongside patients, carers and care providers so that insights from stakeholders within this field are explored. This will enable us to understand what the barriers and facilitators to achieving optimal nutrition and hydration are for those within the community.

The first objective of my PhD is to conduct a systematic review to explore existing research around the use of digital health technology in the context of home care for adults with long term conditions. I seek to understand the context of its use and whether there is evidence of improved outcomes, that can go on to be applied in the context of nutritional care, given the recent drive for adoption within healthcare.

The second objective of my PhD is to then refine my knowledge through conducting an ethnographic study to gain insight and understanding of nutritional practice in the context of home care for people with long term conditions. Through an ethnographic approach and immersing myself within the field, I aim to develop authentic understanding from service users, carers and staff to better understand how nutrition in perceived. I aim to explore (dual burden) malnutrition and how this is perceived and managed from different perspectives. Through knowledge construction, I aim to understand how the role of a dietitian could improve clinical outcomes and quality of life. Given the diverse skills of a dietitian, this could lead to better education of service users, families or staff, identifying areas more research is required or development of nutritional guidelines in the homecare setting, and to inform future use of technology in this context.

1.3 Background to methodologies

1.3.1 Rationale for systematic review

Evidence based practice is the process of identifying, understanding and implementing the most up to date available evidence combined with patient values and clinical judgement to ensure effective clinical decision making (Gopalakrishnan and Rameshkumar 2013). To make available evidence on one health related issue more accessible for decision makers, systematic reviews are conducted of available evidence in relation to one research question, population group, intervention, context and outcome.

The hierarchy of evidence acknowledges systematic reviews as the gold standard for evidence-based practice and the best method to evaluate healthcare interventions. Systematic reviews are positioned at the top of the hierarchy of evidence, which is structured representation of research design methods, ordered in terms of internal validity and applicability. Systematic reviews seek to minimise bias and draw conclusions of the risk bias has on over or underestimating overall results (Boutron, Page, Higgins et al 2019). They are used to pull together data and results from different studies which address the same research question, in a standardised, systematic way. Rigorous and structured methodology and reporting guidelines such as Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) and Consolidated Standards of Reporting Trials (CONSORT) owe themselves to achieving provable methodological quality (PRISMA 2015; Schulz, Altman and Moher 2010). Typically, pooling results of randomised controlled trials has been viewed as the highest quality of evidence in healthcare due to the nature of being able to prove or disprove a hypothesis, assess causal relationships and the extent to which it occurs.

Randomised controlled trials are positioned below systematic reviews, second on the hierarchy of evidence. Randomised controlled trials are quantitative intervention studies which compare treatment effect in a certain population through random allocation of an intervention or control to participants. Randomised controlled trials are considered of good methodological quality if participants and researchers are blinded (unaware) of which intervention (or control) has been allocated. This occurs through allocation concealment (Cochrane

Community 2020). Randomisation of controlled trials helps to alleviate the influence of confounding factors on results and as such, is another benefit of conducting a randomised controlled trial.

Meta-analysis is a statistical process to synthesise sufficiently similar data from multiple studies reporting on the same outcome to determine overall effect size. Meta-analyses systematically assess for heterogeneity, (methodological, clinical or statistical) which can be managed with caution and pooling of data should be considered carefully. If there are studies included of varying quality, results from these studies should be pooled with caution, in which case, data can be differentiated through sub-group analysis to ensure results are combined from the studies of better methodological only. In this way, one can be more confident in the true effect of results (Deeks, Higgins and Altman 2019).

A limitation of systematic reviews is that they are only as good as the available included evidence. Due to relying on secondary data, if the evidence in an area is lacking or of poor or varying quality, this will limit the value of the results a systematic review finds. For this reason, in healthcare innovation where robust evidence (such as randomised controlled trials) is not available, a systematic review will have limited use.

Another significant limitation of randomised controlled trials and systematic reviews is that they can be timely and costly to conduct. As both of these methods follow a rigorous process and well- defined specific research question, they may not address other equally relevant patient outcomes. Therefore, careful consideration of available evidence from non-randomised studies may be necessary in order to fully address all relevant outcomes or adverse effects (Schünemann et al 2019).

Non-randomised studies are generally less timely and costly than randomised-controlled trials. Cross-sectional studies provide insight to certain characteristics in a population at one point in time. Meanwhile cohort studies are used to observe a population over time to assess impact of exposure to a certain intervention. Retrospective studies are historical. They allow past records of participants to be studies up until current day. Prospective studies recruit participants now and observe them over time (Cochrane Community 2020).

In more recent years, the idea of randomised controlled trials and systematic reviews as gold standard has been contested for epidemiological research given their inability to be used to capture qualitative contextual data. There has been greater emphasis within public health and social care to conduct research with a

qualitative aspect in order to provide a narrative. When this is synthesised with quantitative data, it is a powerful tool to present a well-rounded insight to a particular phenomenon by determining overall effect (by quantitative methods), whilst providing context (with qualitative methods) (Vedel et al 2019)..

1.3.2 Rationale for focussed ethnography

1.3.2.1 Background to ethnographic research

The use of ethnography has been documented since Herodotus in 484 BCE in the form of anthropologic systematic investigations of alternative cultures (Ugwu 2017). Since then, ethnography has continued to evolve predominantly in the exploration of non-Westernised societies. As time has progressed so has the sophistication of ethnographic methods and can now be referred to as a method which captures "an exploration of any particular social issue from the perspective of the people concerned" rather than a total population as it once was (Lavenda and Schultz, 2010).

In comparison to the first documented use of 'ethnography', the development from anthropology and ethnology, evolving into ethnography continued into the early 1900s. Work from Malinowski is highly acknowledged within the field and commonly referred to communities (Reeves, Kuper and Hodges 2008). His work within indigenous communities in Australia documented his active participation and observation of the research community, which led to his development of ethnographic methods including the participant observation that we use today (Reeves, Kuper and Hodges 2008).

Ethnography is one of several qualitative health and social research methods used today and, as such, its meaning can vary. The overlap of labels and meaning to researchers has led to the ethnography being used sometimes interchangeably with other qualitative methods such as 'qualitative inquiry', 'participatory research' – these also have hazy semantic boundaries (Hammersley and Atkinson 2007).

Ethnographic research predominantly relies on data collection via participant observation, whereby the researcher becomes immersed within the community of which they are researching (Atkinson and

Hammersley 1989). There is long-standing controversy over whether it is accurate to refer to participant observation as a mere method to collect data within this type of research, which many would agree (Higginbottom, Boadu & Pillay 2013).

Elsewhere it has been argued, however, that participant observation "is not, and cannot be a method" (Tonkin 1984: p.221 cited in Hammersley and Atkinson 2007). This perspective derives from the complexity that the researcher becomes the intermediate for data collection. Age, gender, ethnicity, language and the nature of the researcher therefore become attributes which can impact the level of findings, dependent on the research participants.

Denzin and Lincoln (1994) present a more inclusive view and refer to participant observation as both a research strategy and methodology. This view is shared by Morse and Field (1995) who state it is a mode of study, not merely a "data collection technique" (Hammersley and Atkinson 2007).

More recently, ethnographic research involves the explorative study of social interactions, specific behaviours or beliefs and perceptions that are present within certain social groups, workplaces and communities. In medical education, the use of ethnography has only been documented within the last 60 years, far fewer if we are to analyse its use specifically in healthcare settings (Goodson, Vassar 2011). Regardless, the focal aim of ethnographic research is to offer holistic insights into how people live inclusive of their realities, experiences and opinions within those specific communities or circumstances of which they exist (Reeves, Kuper and Hodges 2008). This therefore makes it a valid tool for providing insight to holistic healthcare practice.

The complex history of ethnography and how it has evolved since the 19th century to be used in a dynamic range of research contexts explains why there it has no one standard definition.

Ethnography boasts flexibility unlike other research methodologies which draw on data collection methods appropriate to each specific context they are exploring. Therefore, having no set definition or structure, does not undermine its value (Hammersley and Atkinson 2007).

1.3.3 What is Ethnography?

Ethnography is "the work of describing culture" which studies real-time, context-specific phenomena as they occur within their natural setting (Higginbottom, Boadu & Pillay 2013). This methodology therefore enables the researcher to immerse themselves within the field to gain rich data through in-depth perspective by way of the "process of learning about people by learning from them", typically over an extended period of time (Roper and Shapira 2000). Ethnographic research elicits unstructured data from a range of methods and should work to present findings as a narrative description. Thorough narratives are the product of analysis and, as such, should include a transparent acknowledgement of interpretation of the significance and purpose of human interaction and behaviour (Atkinson & Hammersley, 1998, p.110).

Given the complex history and evolution of ethnography as a qualitative research methodology, it is by no means surprising that ethnography lacks a specific definition. The absence of a specific definition within qualitative research is not uncommon and does not undermine the value of its use as a research methodology across diverse disciplinary contexts (Hammersley and Atkinson 2007).

What distinguishes ethnography from other qualitative methodologies, and what lends itself to being such an invaluable research tool, is its exploration and connection between the macro and micro. It seeks to explore affiliations between the everyday lived experience and interactions of context-specific phenomena, meanwhile considering the broader cultural structures in order to generate theory and meaning (Savage 2006).

The level of depth within ethnography to generate theory and understanding typically requires lengthy periods of time within the field, spent with reasonably small sample sizes and multiple data collection methods (Higginbottom, Boadu & Pillay 2013). The extensive process of data collection and analysis within ethnography has been well documented as "cultural immersion", whereby the researcher is partially immersed within the field. Partial or full immersion can be present, however, the idea of being fully immersed can create barriers to analytical marginality if the researcher becomes comfortable with the uncomfortable. Similarly, there is risk to data collection and analysis through partial immersion, which may inhibit formation of good relationships with the participants, subsequently limiting the level of depth and detail they may feel comfortable to share (Hammersley and Atkinson 2007). This is a key characteristic of ethnographic research.

The researcher must navigate their way carefully through the process and acknowledge that they themselves are an influence on data collection through being both a researcher and research tool. The nature of the relationship between the researcher and those being researched provides both outsider (etic) and insider (emic) viewpoints respectively. The exploration of multiple realities from these viewpoints provides scope for insightful reflections and knowledge generation (Savage 2006).

Given the evolution of ethnography and its suitability of use within diverse contexts and cultures, focussed ethnographies are becoming more commonplace in numerous disciplines including that of postgraduate research and healthcare. Focussed ethnography is less time intensive, requiring less funding and resources than that of an ethnography which studies whole cultures or communities. Instead, focussed ethnography aims to maintain the methodological processes of standard ethnography, utilising pragmatic and efficient ways of collecting data in context specific phenomena within a sub-culture or discrete community (Higginbottom, Boadu, & Pillay 2013). Morse 1987 presents that 'rapid appraisal' or 'mini-ethnography' lacks inclusion of their problem-focussed and context-specific attributes and so the title of focussed ethnography (FE) is well acknowledged.

Within healthcare research, an investigation of specific values and practices of certain illnesses, or particular healthcare processes, as held by service users and clinicians, ethnography is considered focussed (Magilvy et al 1987). Length of time in the field is reduced because within a distinct population, phenomenon and context, participants are identified who have specific knowledge about a highlighted problem. Given the nature and methodological processes of ethnography and FE, there are acknowledged projections that findings of research conducted by this study design will lead to meaningful and beneficial considerations and application within healthcare practice (Knoblauch 2005).

1.3.4 Limitations of ethnography

As with other qualitative studies, and because ethnography prides itself on its flexible nature – which is transient and adopts different data collection methods dependent on the setting and context of which it is

being used – there is no standard structure or guide on how to best conduct or report ethnographic research. This can be viewed as problematic in health and scientific research.

However, the lack of reporting guidance or standard definition for ethnography does not undermine its value as a research tool, particularly as we have seen in social science and sociological research settings. The complexity of undertaking ethnographic research well should not be underestimated. We have discussed previously in this chapter how ethnography has evolved from anthropology to now be used in a diverse range of contexts and settings, flexibility of its use poses both benefit and risk, dependent on data collection, analysis and presentation.

Lack of standardised guidelines on how to conduct and report on ethnographic data can lead to its use being undermined, especially within healthcare and medical disciplines that typically demand standardised practice for gold standard and robustness of methods and findings. That said, given the growing innovative and diverse research that is demanding overlap between medical, healthcare, technological and other disciplines, it is important that our research questions, and indeed methodologies, evolve too – meanwhile maintaining dignity and duty of producing value research.

The exploratory nature of ethnography can lead to ambiguity when we come to consider obtaining informed consent, given that the research is likely to grow and evolve the longer the researcher is within the field. This can also lead to the research questions and direction of focus evolving, which can cause ambiguity when we consider if informed consent is ever truly achieved. This can be minimised through being open and honest from the beginning of the research project and throughout, ensuring participants are aware of what they are agreeing to, and of their rights to withdraw up until a specified date.

1.3.5 Rationale for ethnographic method

Grounded theory, thematic analysis and careful use of semi-structured interviews and or focus groups to collect and produce data are common in qualitative research (Braun and Clarke 2006). It is well reported that

these methods can offer flexibility whilst maintaining robustness and methodological rigour – to some extent – as far as the complexity of qualitative methods and reporting are concerned.

Alternative qualitative methods such as a set of semi-structured interviews with care staff and patients at one given time are likely less time and labour intensive, providing insight at one snap-shot of time. For this reason, ethnography can be criticised, owing to the length of time in the field, continuously collecting and analysing data (Pope, Royen and Baker 2002).

Ethnographic research is a method whereby the researcher immerses themselves fully within the community being researched. This provides opportunity for researcher to collect data within the social setting and to perceive things as they naturally occur so that observations can be recounted and interpreted in a truly reflective manner. The purpose of this method is for readers to gain insight and an understanding of how it is to be part of the selected social setting (Paradis, Leslie & Gropper 2016).

This method in healthcare research empowers and entitles the researcher to challenge the status quo, by acting as a fresh pair of eyes within the field. Ethnography provides opportunity to observe what people do and compare that to what they say they do, which could not be achieved through a one-off interview alone. It therefore can be a powerful tool for providing reflection and feedback for clinicians and service leaders to reconsider current processes and practices (Paradis, Leslie & Gropper 2016).

More recently, the value of ethnography has been appreciated within healthcare and is now advocated within the NHS as a key qualitative method to reflect how people actually live through researching them over time (NHS England 2017). The process of participatory observation and participatory research is now viewed as a sustainable driver for research, being that it is inductive and diverse, reflecting different ontological epistemological underpinnings and aims to encourage learning about people alongside them, rather than studying people with a predetermined agenda in mind. Active participation of service users and stakeholders from the outset and throughout is recognised as a key method to drive and develop new policies for the future of healthcare (NHS England 2017).

2 The effect of telehealth versus usual care for home care patients with long term conditions: a systematic review and meta-analysis and qualitative synthesis

2.1 Introduction to Chapter 2

This chapter aims to explore the evidence which underpins the rationale for this PhD. This chapter is in essence the systematic review and meta-analysis which I conducted within my early stages of this PhD journey and which is now published in the Journal of Telecare and Telemedicine. Section 2.2 provides in a brief background and outlines study aims and objectives. Section 2.3 provides the methodology used for my systematic review and meta-analysis. In Section 2.4, the results are presented which includes meta-analyses for all primary and secondary outcomes, qualitative findings and finally a synthesis of both the quantitative and qualitative results. Section 2.5 provides discussion of this review in line with other publications and methodological rigour. In Section 2.6 I draw conclusions from this study.

Section 2.7 explores the implications of this systematic view and provide rationale for the next steps in my PhD journey.

2.2 Background to systematic review

My early reading of available evidence within this population and group and setting identified that nutrition was not a measured outcome, as explained in Chapter 1. My first step therefore was to systematically review whether telehealth was superior when compared to usual home care on quality of life in people with long term

conditions. I focused on quality of life as the primary outcome and physical function, disease specific outcomes, depression, anxiety, inpatient bed days of care as secondary outcomes given their documented association with nutritional wellbeing.

2.2.1 Aim of Systematic Review

The aim of this research is therefore to conduct a systematic review on the evidence of telehealth interventions in the community compares to usual care and its impact on quality of life.

2.2.2 Study Objectives

To conduct a systematic review of studies, of any study design, meeting the following criteria:

- Adults live at home with a long-term condition
- Telehealth, as defined as the remote exchange of medical data using electronic equipment between a service user and healthcare professional, has been used instead of usual home care (homecare nursing and visits for assessment, diagnosis, treatment management plans, services user and carer support)
- Quality of life (either quantitatively or qualitatively) or cost effectiveness has been measured.

2.3 Methods for systematic review

2.3.1 Search Criteria

Medline and CINAHL databases were searched for studies using medical subject headings and keywords to include terms for: long-term conditions OR life-limiting conditions AND telehealth OR tele monitoring. Terms were agreed with a subject librarian and author team. Full details of the search strategy are in Appendix 1.

2.3.2 Study Selection

Titles and abstracts were screened to identify potentially relevant articles fitting the inclusion criteria (Table 1). The full text of these articles were then reviewed with further irrelevant studies excluded at this stage. Final articles were checked in terms of relevance to the research question and inclusion criteria by a second author.

Table 1. Inclusion and exclusion criteria

	Inclusion criteria	**Exclusion criteria**
Population	• Adult population (over 18years) • Diagnosis of one or more chronic condition • Home care patients only	• Under 18 years • Participant age range not stated • No clear diagnosis of chronic condition • Cancer and Chronic kidney Disease (as treatments which cure are available)
Intervention	• Remote exchange of medical information between a service user and healthcare professional	• Non-health related smart home technology (energy consumption, home security) • Remote consultation • Internet education • Remote monitoring • Motivational messages or reminders • Telephone follow up
Comparator	• Standard home care • Face to face visit from healthcare assistant or district nurse	• Care in nursing homes, residential homes or sheltered accommodation • Hospital based inpatient care
Outcomes	• Quality of life scales • Qualitative data depicting quality of life • Cost-effectiveness •	• No quality of life results • No cost effectiveness reported
Study Design	• Qualitative, • Quantitative, • Mixed methods	• No design restriction
Language type	languages included	language restriction
Date of publication	90- present	pers published pre-1990 as they are ely to relate to technologies which are

		w obsolete due to the recent surge in hnology interest and advances
Type of publication	Research papers which have undergone peer review	• Magazine articles • Book chapters • Dissertations and theses

2.3.3 Data Extraction

Data were extracted from each of the studies and included study design, sample size, demographics and medical condition of the population, intervention description, comparator and outcomes related to quality of life and cost-effectiveness.

2.3.4 Data analysis

Where available, intention to treat data was extracted in preference to completer analysis data. Meta-analyses were conducted to combine results of two or more sufficiently similar studies measuring comparable outcomes. Software used for meta-analyses in this paper was Rev Man 5 and a random effects model was used. Heterogeneity was assessed using the I^2 statistic. Sensitivity analyses was conducted to see if the results were robust to removal of studies with a high risk of bias.

Reporting of qualitative results was narrative, using thematic analysis and based on qualitative synthesis recommendation by Walsh 2005. Once complete, this was then peer reviewed by a second author.

2.3.5 Assessment of Risk of Bias

The Cochrane tool for assessing risk of bias was used to assess bias of random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete data outcome and selective reporting of quantitative studies. Critical Appraisal Skills Programme Checklist was used to assess qualitative research.

2.3.5.1 Random Sequence generation

- Low risk of bias: computer generated sequencing
- High risk: no comment on attempt to randomise sequence generation
- Unclear risk: sequence generation stated but unclear reporting on methods to achieve it

2.3.5.2 Allocation concealment

- Low risk: opaque, sealed randomised envelopes
- High risk: envelopes distributed but no further detail on random allocation or distribution
- Unclear risk: no mention of any attempt to conceal allocation

2.3.6 Blinding of participants and personnel

Due to the nature of the intervention, blinding was not appropriate hence this aspect of bias estimation was deemed not applicable.

2.3.7 Blinding of data outcome

Due to the nature of the intervention, blinding was not appropriate hence this aspect of bias estimation was deemed not applicable.

2.3.8 Incomplete outcome data

- Low risk: no missing outcome data, outcome data same across trial arms
- High risk: missing outcome data, large variances of participants remaining across trial arms by follow up
- Unclear risk

2.3.9 Selective reporting

- Low risk: all pre-defined outcomes are reported and explained, missing data is highlighted with explanation

- High risk: pre-specified outcomes are not later reported or discussed
- Unclear risk

2.3.10 Sensitivity analysis

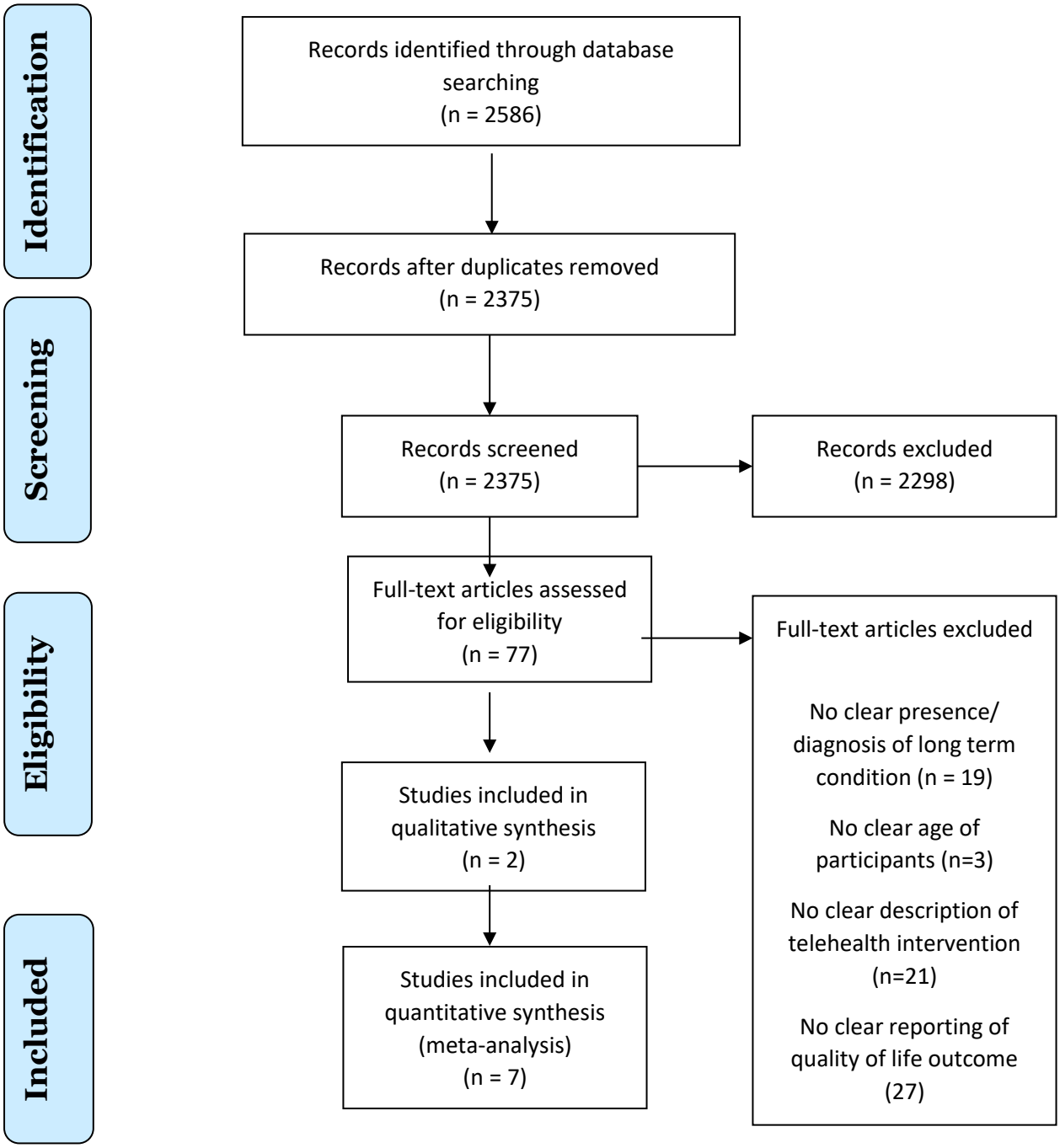
The five different domains to judge bias were useful to determine attributable value of results for included studies. Combining studies of different methodological rigour through meta-analyses were useful to obtain results of a larger sample. Sensitivity analysis was conducted on meta-analyses to differentiate the impact bias had on overall combined results.

2.4 Results of the systematic review and meta-analyses

2.4.1 Study Selection

The search yielded 2568 citations, once duplicate citations had been removed, 2375 papers remained to be screened. Of these, 2298 were rejected by screening the title and abstract. The remaining 77 full-text articles were assessed for eligibility; 19 were excluded due to a lack of formal diagnosis, 21 provided no clear description of the telehealth intervention and 29 did not report quality of life as an outcome measure. Nine studies were included in the review, 7 of which were quantitative, 2 of which were qualitative- the PRISMA flowchart is detailed in Figure 2.

Figure 2: Preferred Reporting Items in Systematic review and Meta-Analysis (PRISMA) Flowchart for Search Strategy



Reproduced from Moher et al (2009)

2.4.2 Characteristics of Included Studies

A total of 9 studies were included in this review, 2 of which were qualitative papers (Gale and Sultan 2012; Gorst, Coates and Armitage 2015). Of the quantitative research, 1 was a single site cohort study (Noel et al 2004), 2 were multi-site cluster trials (Cartwright et al 2013; Henderson et al 2013) and the remaining 4 studies were randomised trials (McDowell et al 2014; Lusignan et al 2001; Pecina et al 2013; Lewis et al 2011).

2.4.3 Study Participants

A total of 2611 home care adults living with chronic condition(s) were involved in this review (Table 2). Sample size varied among the studies from 7 to 1201 participants. Studies were predominantly conducted in the UK (78 percent), 5 of 9 in England, 1 in Ireland and 1 in Wales. 2 studies were carried out in the United States.

Of the nine included papers, 8 provided information on gender. The distribution of males to females included equates to 1489 (59 percent) and 1042 (41 percent) respectively.

Age of participants varied between 49 and 90 years old although mean age calculates at 71 years old. All participants have a formal diagnosis of at least one chronic condition, the most prevalent condition being Chronic Obstructive Pulmonary Disease (COPD). 4 of 9 papers included participants with only this condition, 2 papers focussed on people with only Chronic Heart Failure (CHF). Other remaining studies included patients with a diagnosis of Diabetes Mellitus (DM) and presence of co-morbidity (CHF and DM, CHF and COPD, COPD and DM or CHF, COPD and DM).

2.4.4 Interventions

Each of the included studies described a technology enabled intervention which involved the remote exchange of medical information between a service user and assigned health care professional. All study participants

were provided with devices on which patients were expected to measure vital signs including weight, blood pressure, temperature and pulse oximetry. Three studies specified that recordings were expected to be measured and sent daily (McDowell et al 2014; Pecina et al 2013; Lewis et al 2011).A qualitative study implemented a new telehealth intervention whereby COPD patients were able to send vital signs to a Community Respiratory Service (CRS). This included their oxygen saturation, blood pressure, weight, and temperature every weekday.

Table 2. Table of study characteristics

	Country of origin	Study Type	Number of participants: Total (control vs intervention)	Gender (m/f)	Age range (or SD)	Long term condition diagnosis	Description of telehealth intervention	Length of intervention	Total length of study including follow up	Quality of life measures
Lewis, Annandale, Warm et al 2010	*Wales, UK*	*Quantitative: Randomised trial*	*40 (20/20)*	*20/20*	*63-79*	*Primary diagnosis of moderate to severe COPD*	*6 month telemonitoring in addition to standard care. Questions plus temperature and pulse oximetry sent every evening 02.00am for nurse to review in the morning*	*6 months*	*12 months (6 months TH then 6 months standard care vs 12 months standard care)*	*Measured: St Georges Respiratory Questionnaire, Hospital Anxiety and Depression Score, EuroQuol-5D Questionnaire*
McDowell, McClean, Gibbon et al 2014	*Northern Ireland, UK*	*Quantitative, Randomised clinical trial*	*100 (52/48)*	*38/62*	*70 (7)*	*Primary diagnosis of moderate to severe COPD*	*Standard programme care plus HomeMed: answer questions plus blood pressure and finger probe reading- nurse read within 10 minutes of data arrival*	*6 months daily*	*6 months*	*St Georges Respiratory Questionnaire, Hospital Anxiety and Depression Score, EuroQuol-5D Questionnaire*
Pecina, Hanson, Houten et al 2013	*USA*	*Quantitative: Randomised controlled trial*	*166 (89/77)*	*78/88*	*79 (9)*	*Presence of chronic disease. Not specific*	*Intel Health Guide to collect biometric data (blood pressure, weight, pulse, temperature, pulse oximetry, peak flows). Daily readings and videoconferencing available. Time delay between monitoring and nurse viewing results not specified.*	*12 months*	*12 months*	*Physical and mental score on the Short Form Health Questionnaire (SF-12v1). Patient Health Questionnaire (PHQ 9). Barthel Index and self-reported health status*
Henderson, Knapp, Fernandez et al 2013	*London, UK*	*Cluster Randomised Controlled Trial*	*965 (431/534)*	*521/384*	*70 (11)*	*COPD, Chronic Heart Failure, Diabetes*	*Weighing scales, pulse oximeter, blood pressure cuff, glucometer. Different equipment for participants in different regions based on health care provider*	*12 months*	*12 months*	*Quality Adjusted Life Years, ICECAP-O, BriefSTAI and Centre for Epidemologic Studies Depression Scale (CESD-10)*

Cartwright, Hirani, Rixon et al 2013	*London, UK*	*Cluster Randomised Controlled Trial*	*1201 (531/670)*	*723/478*	*70 (11)*	*COPD, Chronic Heart Failure, Diabetes*	*Weighing scales, pulse oximeter, blood pressure cuff, glucometer, symptom reports transmitted. Second generation system: non-immediate data analysis*	*12 months*	*12 months*	*SF-12, EQ-5D, BreifSTAI, CESD-10*
Lusignan, Wells, Johnson et al 2001	*Guildford, UK*	*Randomised controlled pilot trial*	*20 (10/10)*	-	-	*Diagnosis of chronic heart failure*	*NAIS memory Blood Pressure Watch- pulse and blood pressure plus weighing scales and video consultation equipment*	*12 months*	*12 months*	*GHQ and Chronic Heart Failure symptomatology questionnaire*

Noel, Vogel and Erdos et al 2004	*Connecticut, USA*	*Single blind, single site randomized large sample study*	*104 (57/47)*	*101/3*	*71 (54-90)*	*Complex heart failure, COPD, Diabetes*	*Peripheral devices to collect blood glucose, blood pressure, temperature, 3-lead electrocardiogram, stethoscope for heart and lung sounds, pulse oximetry and weight. Pain level 0-9 via self-reported questionnaire. Data transmitted via facilities electronic database (VISTA)*	*12 months*	*12 months*	*No validated scale. Objective and subjective measures of self-reported quality of life taken and recorded at baseline, and quarterly until 12 months (cognitive status, HBA1C levels, functional level, patient satisfaction, self-rated health status). Cost data were recorded 6 months preceding the study and 6 months during participation.*
Gorst, Coates and Armitage 2016	*Sheffield, UK*	*Qualitative using IPA analysis.*	*8*	*3/5*	*68 (58-84)*	*COPD*	*6 with small sized telehealth equipment: peripheral devices to take vital sign recordings. 2 had large telehealth equipment which allowed them to view their graphs. All patients monitored blood pressure, oxygen level, pulse rate and temperature. 2 patients with larger equipment monitored weight*	*Patients already been using telehealth equipment to manage condition, no intervention period.*		*Face to face interviews, semi structured interview template. Interpretative Phenomenological Analysis used to gain complete and in-depth understanding of patient experiences of illness and health care.*
Gale and Sultan 2013	*Birmingham, UK*	*Qualitative*	*7*	*5/2*	*67 (57-85)*	*COPD*	*Blood pressure, weight and temperature every weekday sent to Community Respiratory Service team*	*9 months*	*9 months*	*Situated interviewing (at patients homes). Observations of the home made. Thematic analysis used*

This intervention lasted for 9 months prior to the commencement of interviews (Gale and Sultan 2012). Only one qualitative study reported on patients with pre-existing telehealth to gain an understanding of the longer term (exceeding 12 months) impact of telehealth on quality of life outcomes (Gorst, Coates and Armitage 2015). Most other quantitative studies only followed up participants for 12 months.

Two studies reported shorter term outcome measures at 3, 6 and 9-month intervals (Noel et al 2004; Lusignan et al 2001). One study (Pecina et al 2013) reported at 6 and 12 months and 1 other study measured only from baseline and at 6-month follow up (McDowell et al 2014). Cartwright et al (2013) and measures short term outcomes at 4 months and 12 months for long term outcome assessment (Cartwright et al 2013).

2.4.5 Comparator

All but two studies included a comparator which was standard health and social care. Detail to what this entailed in terms of frequency of visit or contact with community health professional for each study is limited. Cartwright et al (2013) stated usual homecare consisted of pre-established tailored care plans of multidisciplinary teams. They report visit frequency depended on condition severity and ranged from between once per week to once per year dependent on the patient.

The two qualitative studies reported on patients who had been using telehealth anyway or for a nine-month study period (Gale and Sultan 2012; Gorst, Coates and Armitage 2015). For these studies, there was no comparator being investigated.

2.4.6 Outcome Measures

Studies measured quality of life measured using EQ-5D, EQ-VAS, self-rated health and qualitative reporting methods (McDowell et al 2014; Pecina et al 2013; Cartwright et al 2013; Lewis et al 2011). Proxy measures to quality of life included psychological wellbeing measured by mental component score (MCS), Kokmen test and 28-item General Health Questionnaire (GHQ) (Cartwright et al 2013). Depression and anxiety were measured by Hospital depression and anxiety (HADS- Depression or HADS-anxiety), CESD-10, Patient Health Questionnaire (PHQ9), Brief-STAI (McDowell et al 2014; Pecina et al 2013; Cartwright et al 2013;

Lewis et al 2011; Henderson et al 2013). Physical function was measured using the physical component score (PCS) and Barthel Index (Pecina et al 2013; Cartwright et al 2013). Disease specific quality of life was measured by Chronic Heart Failure Questionnaire and St Georges Respiratory Questionnaire for COPD (SGRC-C) [11,26,29]. Cost effectiveness was measured as Quality Adjusted Life Years and ICECAP-O (Henderson et al 2013).

2.4.7 Assessment of bias

McDowell et al, 2014, Lewis et al, 2011 and Cartwright et al, 2014 were all considered to be a t lower risk of bias than the other studies (Figure 3). Bias was assessed for each included study based on the criteria developed by the Cochrane Handbook for systematic reviews of Interventions (Higgins 2011).

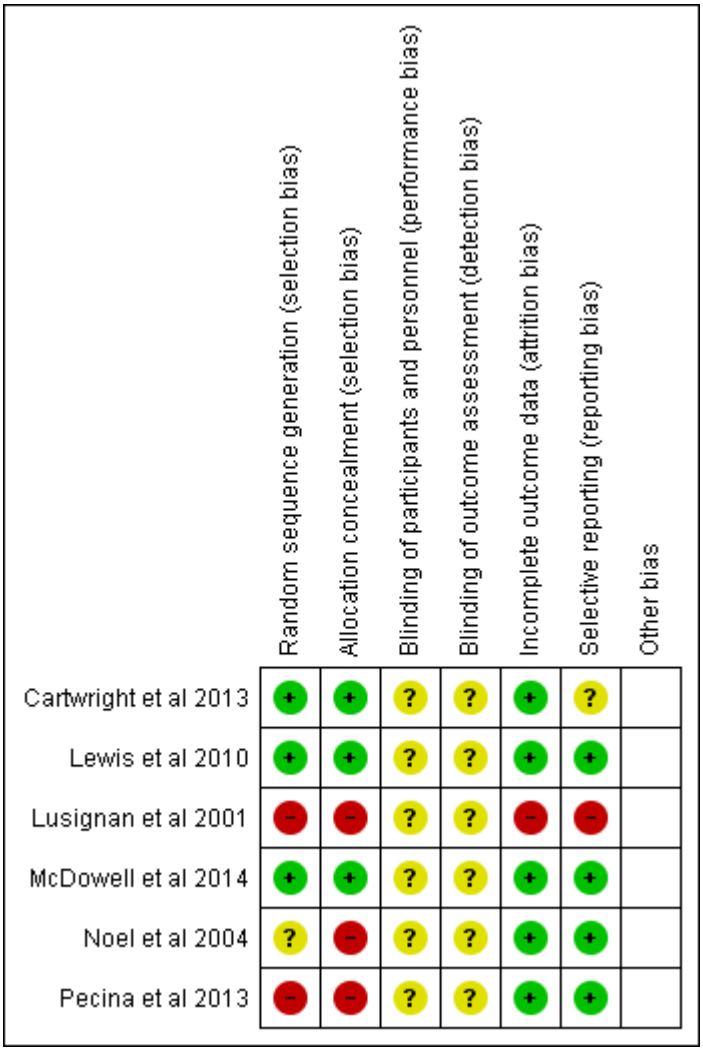


Figure 3: Assessment of bias table

2.4.8 Meta-analyses

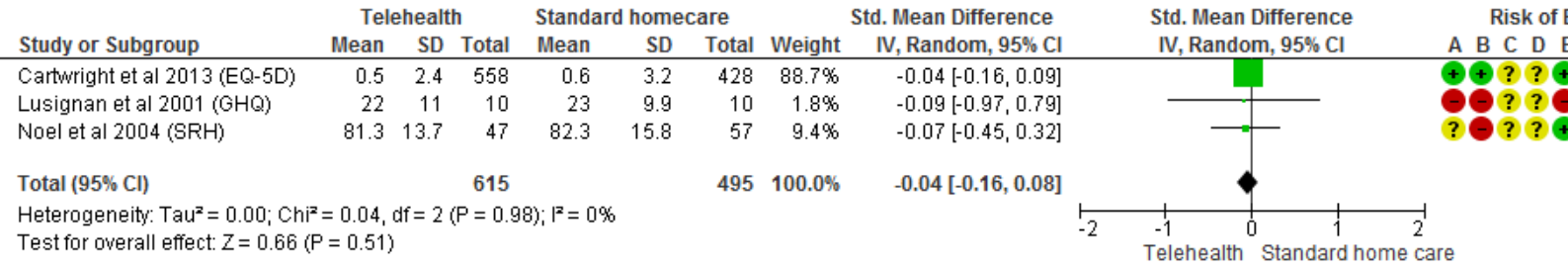
As discussed in Chapter 1, Meta-analyses are a method of pooling data from different studies which report on the same or sufficiently similar outcome to report on overall mean effect across studies and assess statistical significance. Meta-analyses systematically assess for heterogeneity, but pooling of data should be considered carefully and ensure inclusion of studies with high or similar quality to accurately determine overall effect shown (Deeks, Higgins and Altman 2019). The overall mean effect and the spread of this data is represented by a diamond at the right-hand side of the forest plot/figure. Statistical significance is determined by the positioning of the diamond at the bottom. If the diamond overlaps 0, the result shows no statistically significant difference between study groups. This will result in a p value > 0.05. The forest plots are weighted by study size and the 'traffic light' labelling of the study takes into account the methodological rigour based on the domains listed in a previous section.

2.4.9 Quality of life

Pooling the results in meta-analyses from the studies measuring quality of life show that telehealth versus standard home care are not statistically significantly different in terms of change in quality of life at 3 months (Figure 4) 6 months (Figures 5 and 6) 9 months (Figure 7) and 12 months (Figures 8 and 9).

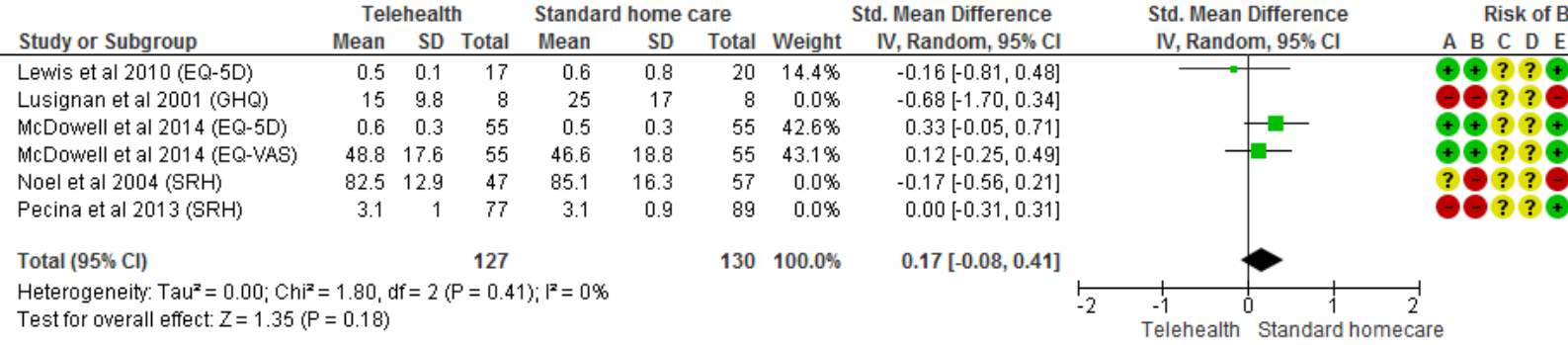
Sensitivity analysis removing studies at high risk of bias was conducted on results from 6 months (Figure 5 and 6) and 12 months (Figures 8 and 9) but this had a negligible effect on the results.

Figure 4: Quality of life at 3 months follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 5: Quality of life at 6 months follow up



Risk of bias legend
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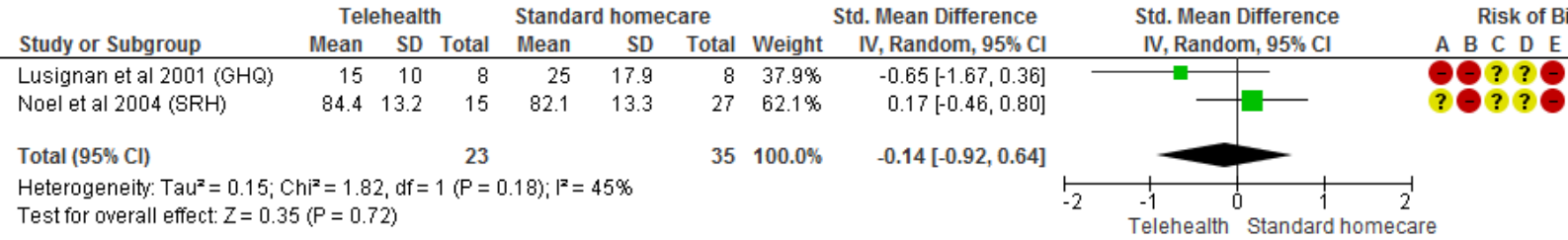
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 6: Sensitivity analysis for quality of life at 6 months follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
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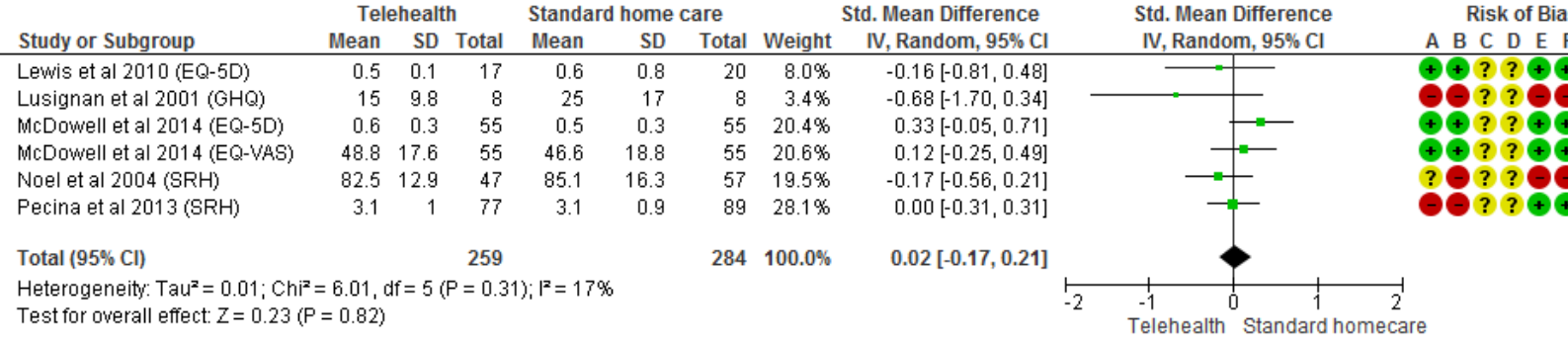
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 7: Quality of life at 9 months follow up



Risk of bias legend
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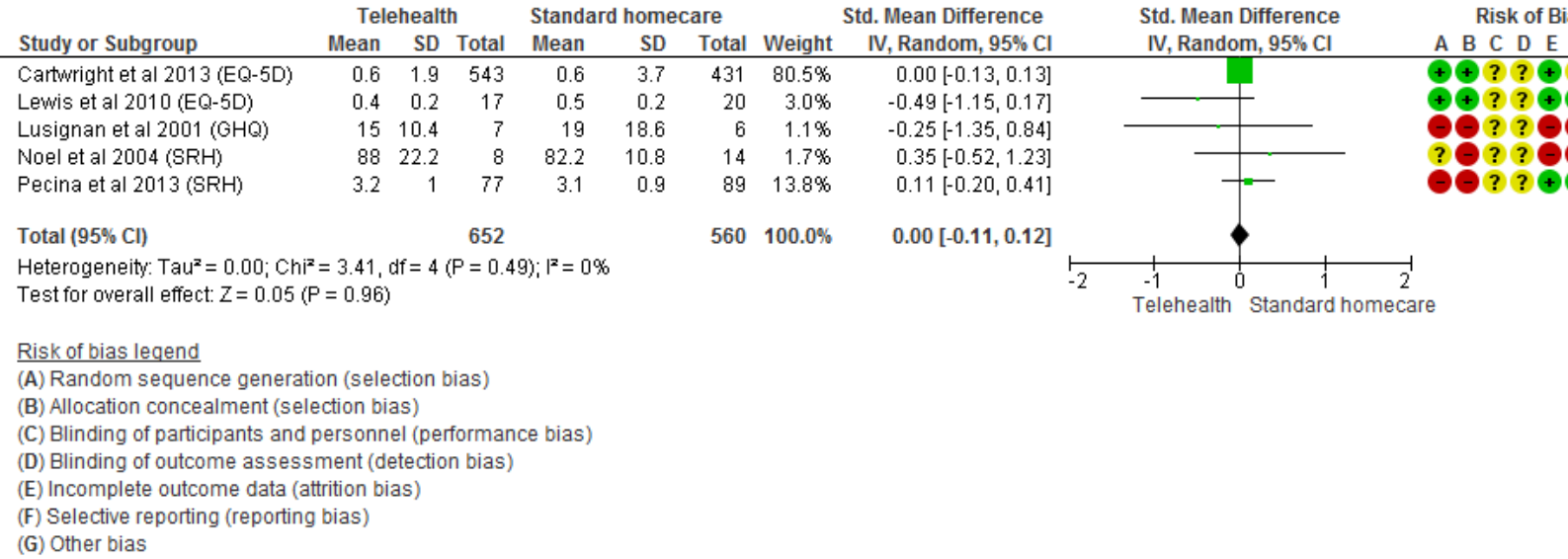
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 8: Quality of life at 12 months follow up



Risk of bias legend
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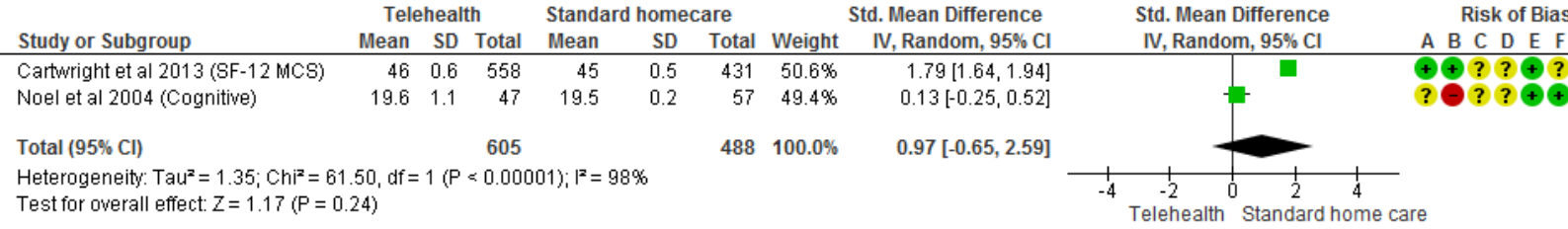
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias



Risk of bias legend
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(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 9: Sensitivity analysis for quality of life at 12 months follow up

2.4.10 Psychological wellbeing

Figures 10, 11 and 12 show telehealth and standard home care are not statistically significantly different in terms of change in psychological wellbeing at 3, 6 and 12 months. These results are not statistically meaningful because of the minimal effect size, however they are arguable clinically meaningful as they show that substituting care may not be detrimental to service users.

Figure 10: Psychological wellbeing at 3-month follow up

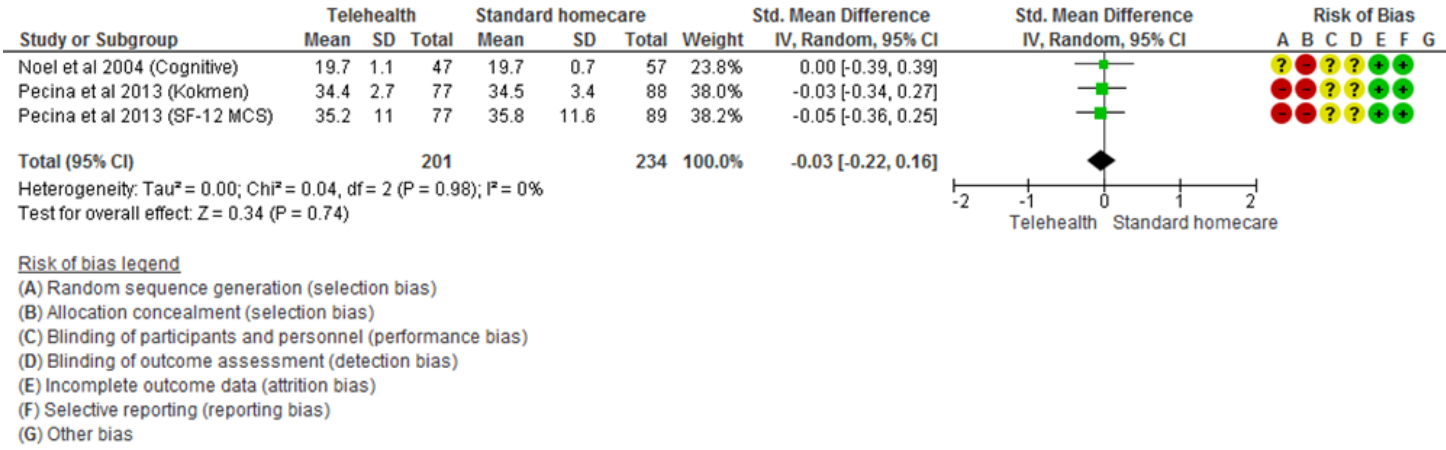


Figure 11: Psychological wellbeing at 6-month follow up

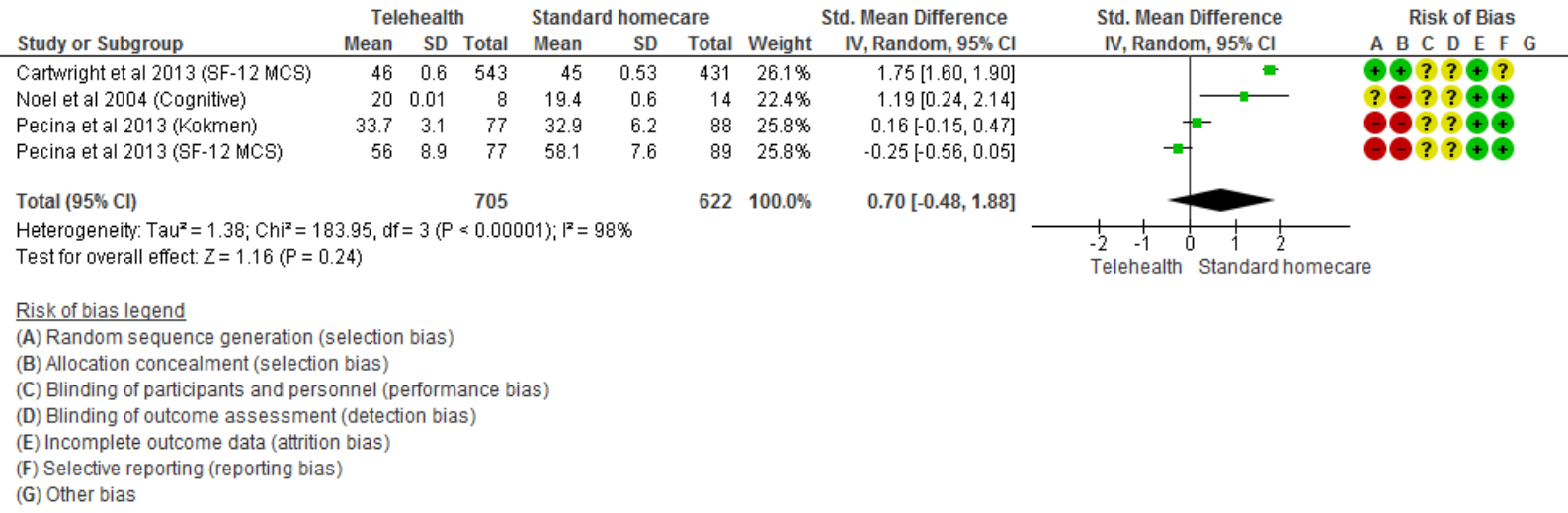
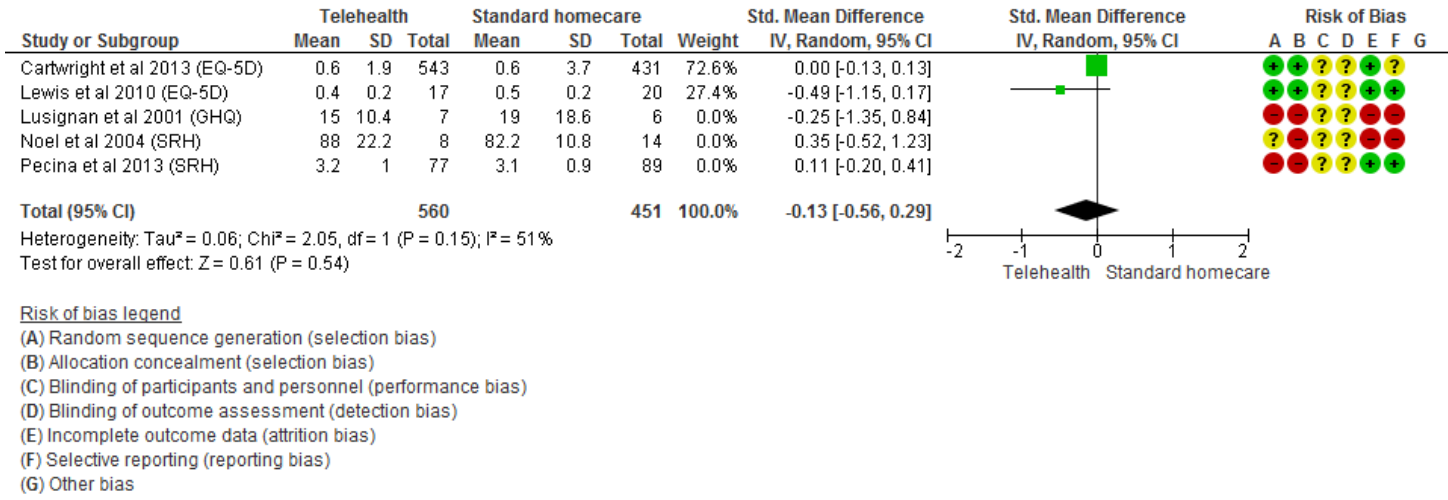


Figure 12: Psychological wellbeing at 12-month follow up



2.4.11 Physical function

These meta-analyses show telehealth and standard home care are not statistically significantly different in terms of change in patients' physical function at 3 months (Figure 13), 6 months (Figure 14) and 12 months (Figure 15). These results consistently favour telehealth, but the effect size is negligible and not clinically important.

Figure 13: Physical function at 3-month follow up

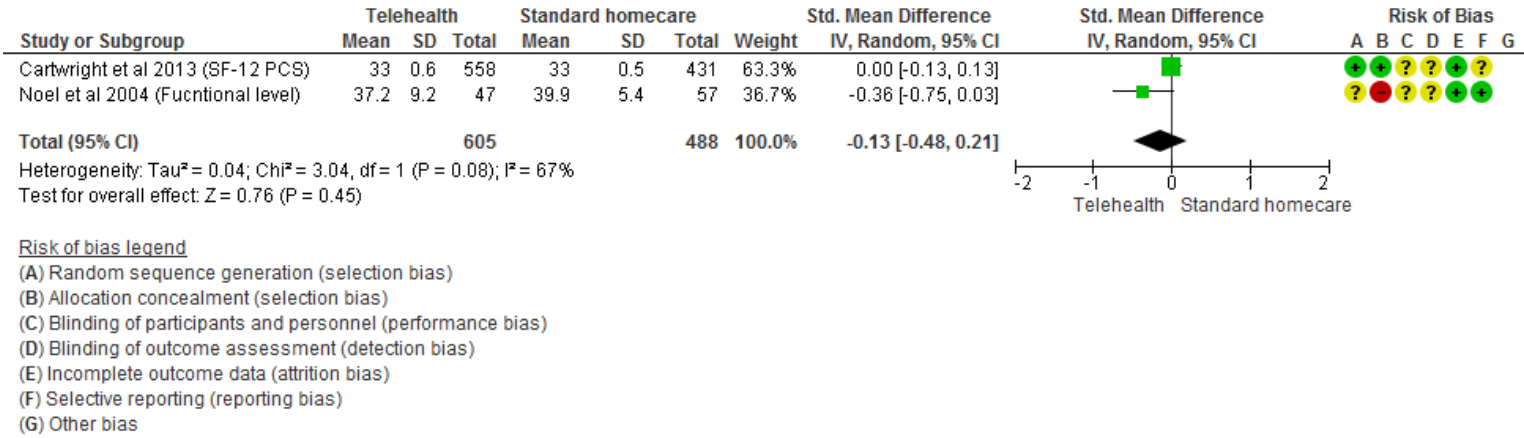
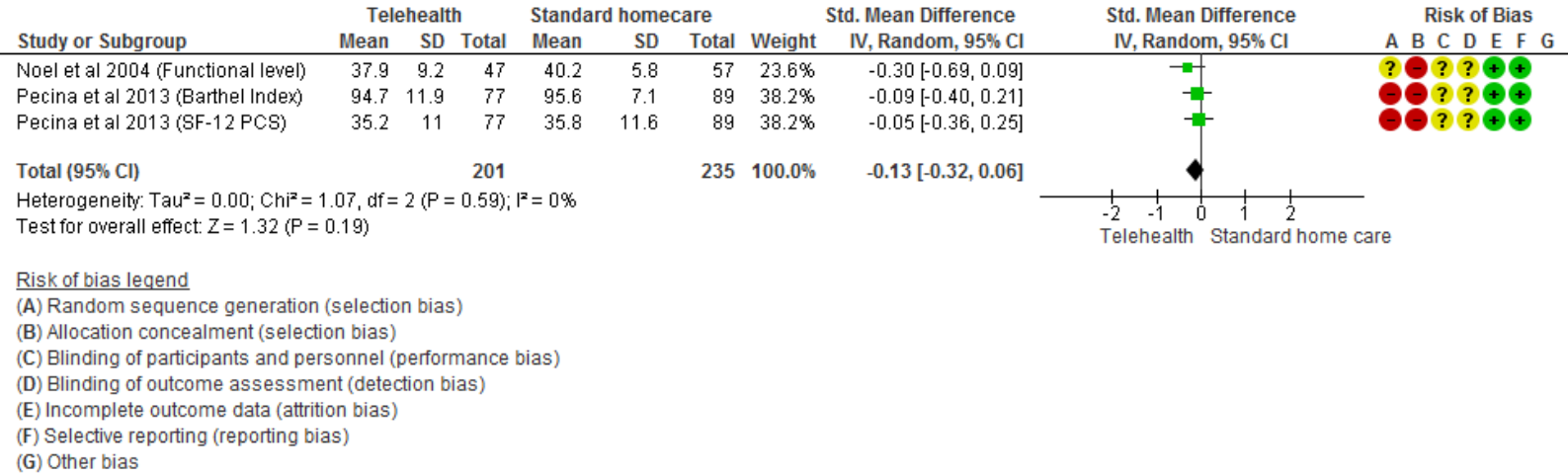


Figure 14: Physical function at 6-month follow up



Risk of bias legend
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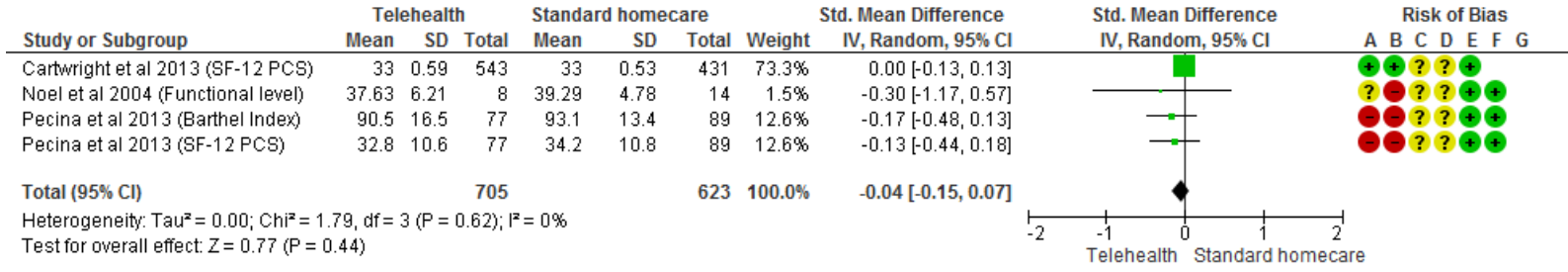
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 15: Physical function at 12-month follow up



Risk of bias legend
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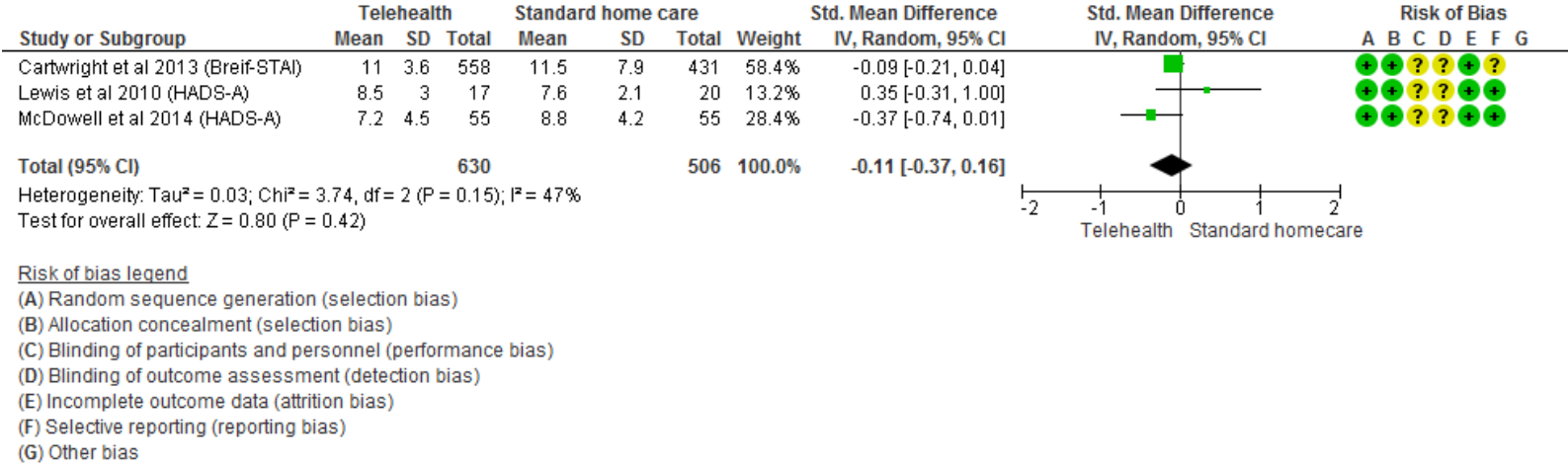
(F) Selective reporting (reporting bias)
(G) Other bias

2.4.12 Anxiety

Figure 16 and 17 present results on anxiety at 6 and 12 months respectively. These meta-analyses combine low level bias studies only yet are still statistically not significant in terms of a difference in change in anxiety scores between telehealth and standard home care.

Figure 16: Anxiety at 6-month follow up



Risk of bias legend
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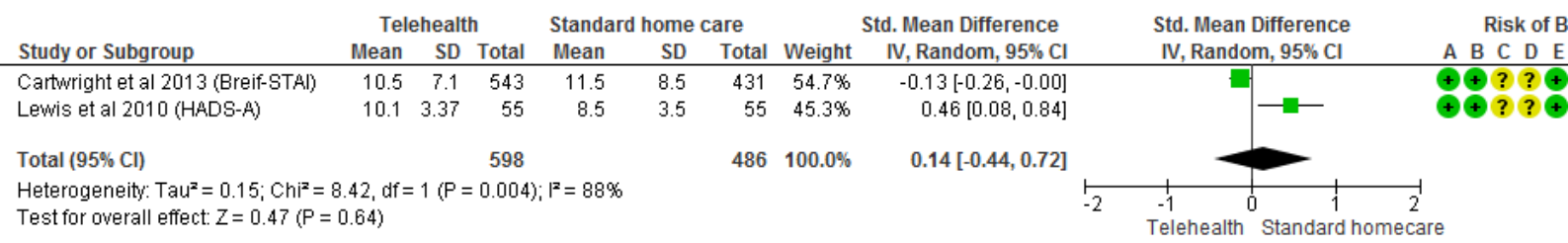
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 17: Anxiety at 12-month follow up



Risk of bias legend
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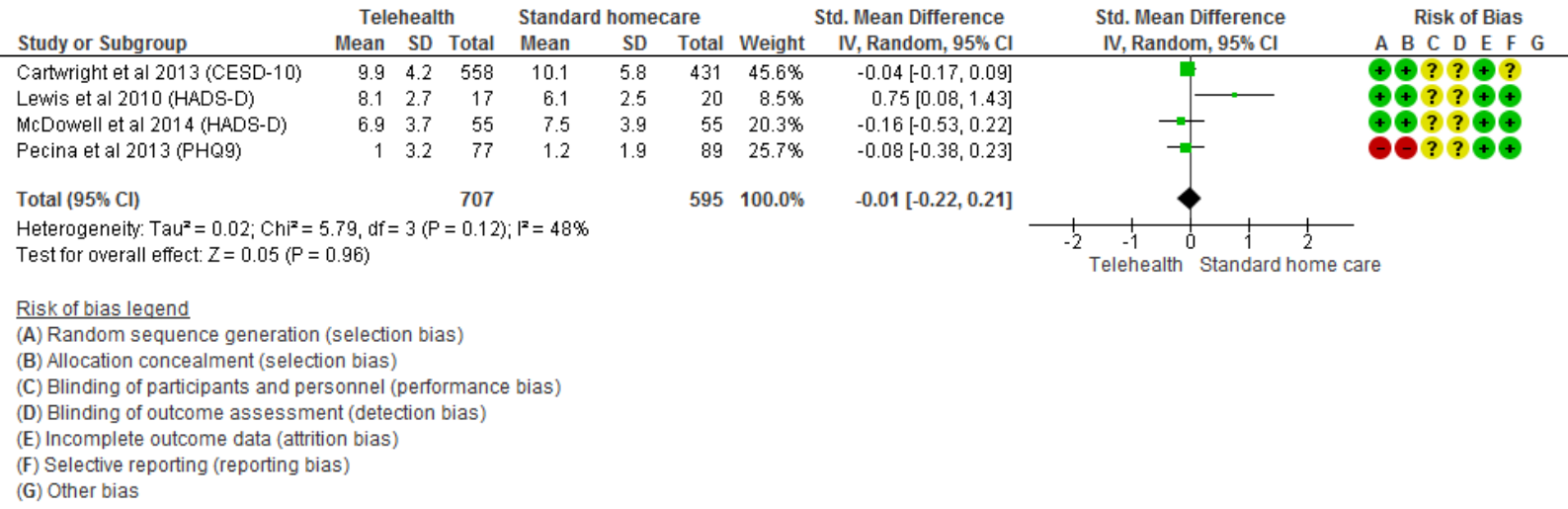
(F) Selective reporting (reporting bias)
(G) Other bias

2.4.13 Depression

These meta analyses show telehealth and standard home care are not statistically significantly different with regard to change in patients' depression scores at 6 and 12 months (Figures 18, 19 and 20, 21).

Sensitivity analysis was conducted on data at 6 months and 12 months to combine low level bias studies only to assess whether this influenced the results. Results from both sensitivity analyses were not significantly different to primary findings. Change effect size is minimal at both time intervals which reflects no clinically meaningful difference result.

Figure 18: Depression at 6-month follow



Risk of bias legend
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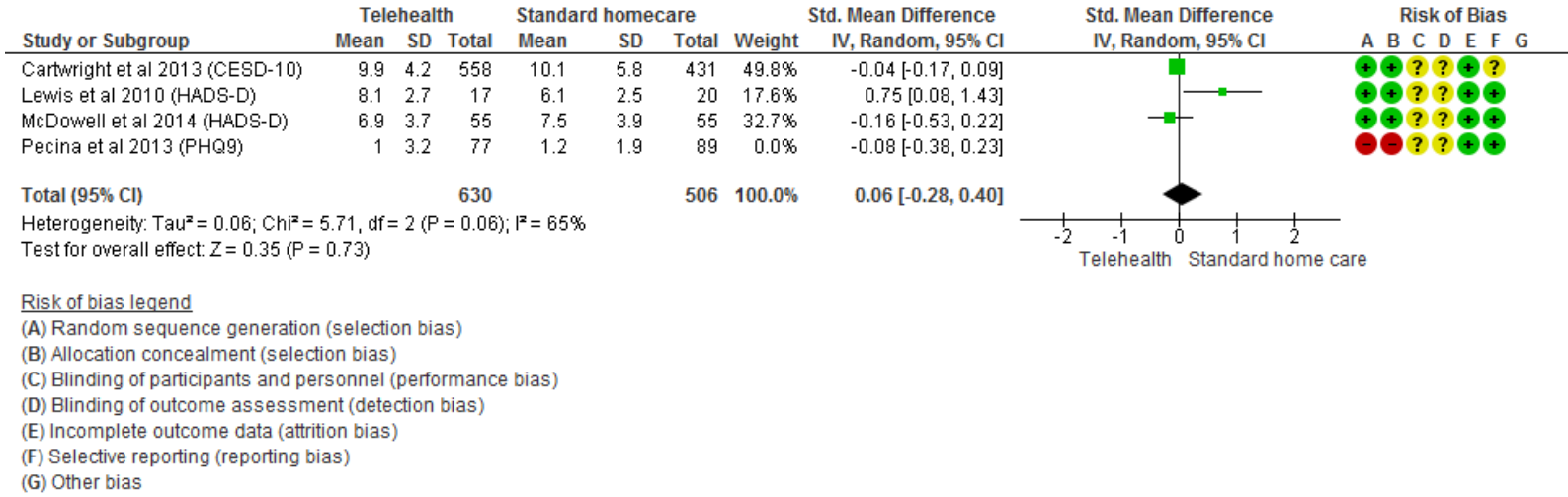
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 19: Sensitivity analysis for Depression at 6-month follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
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(C) Blinding of participants and personnel (performance bias)
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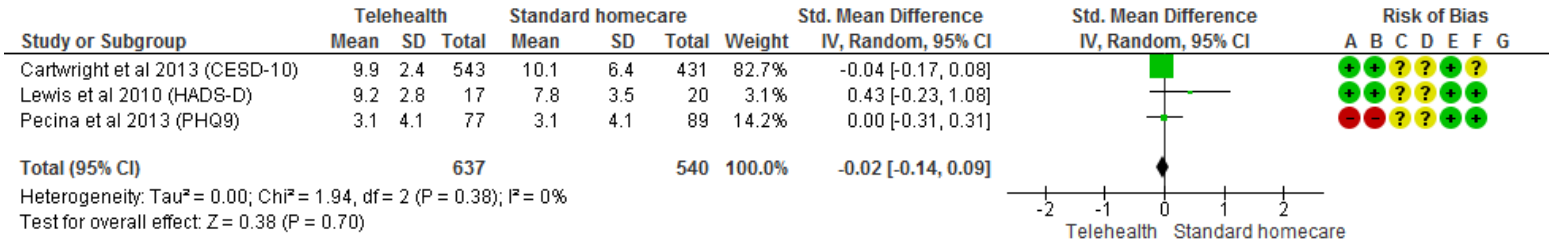
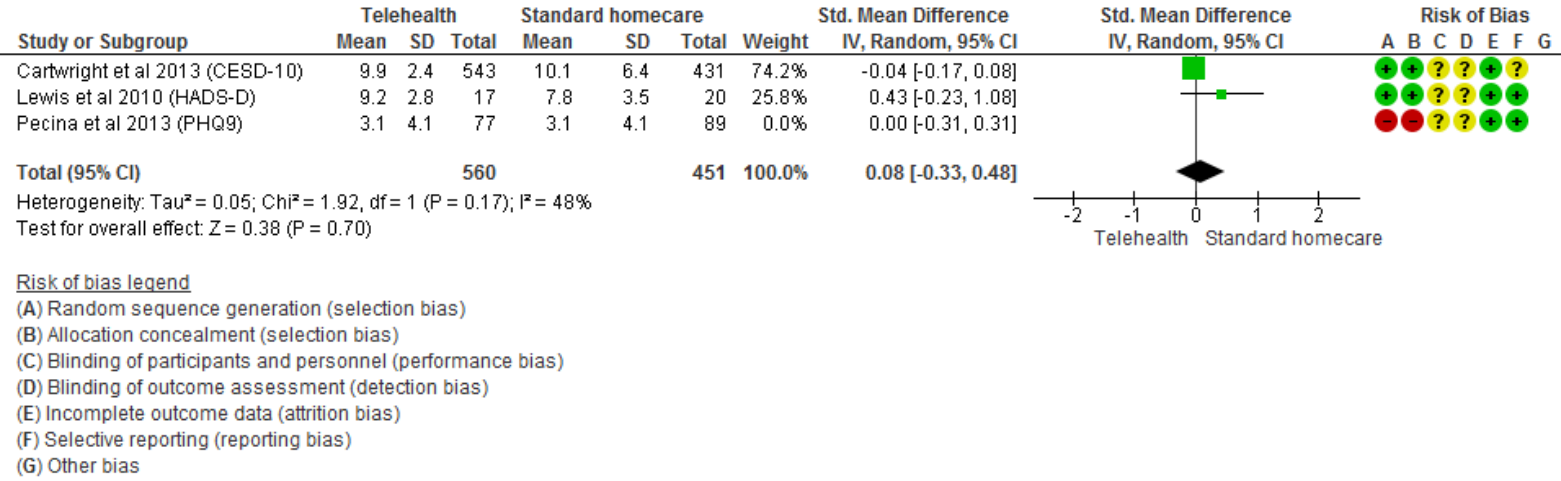
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 20: Depression at 12-month follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 21: Sensitivity analysis for Depression at 12-month follow



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

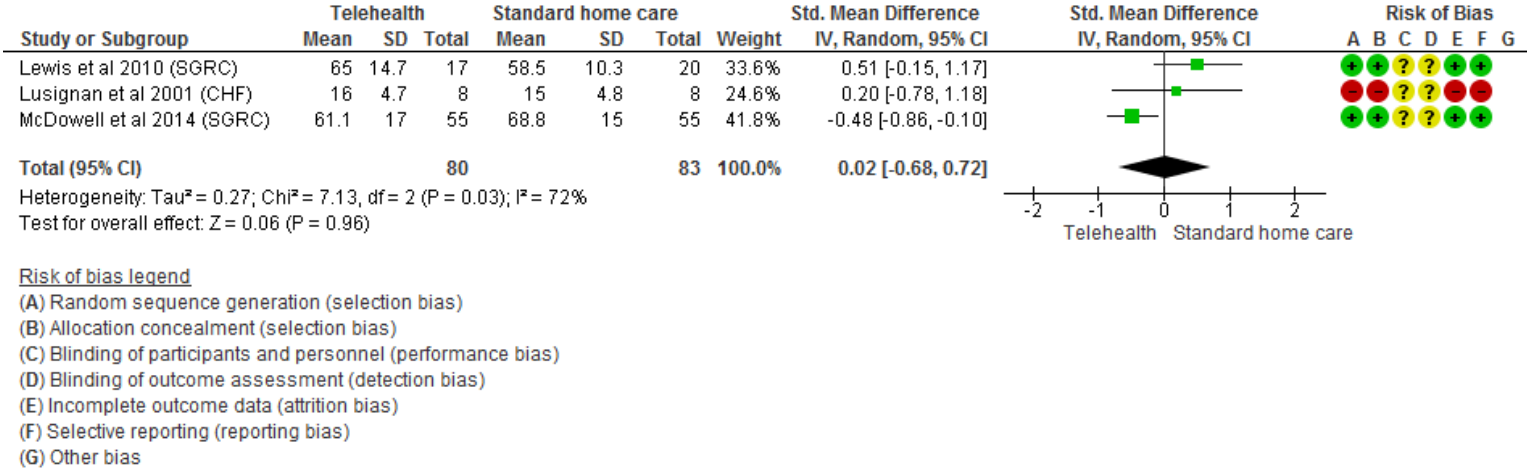
2.4.14 Disease Specific outcomes

Results from data on disease specific outcomes at 6 months (Figure 22,23) and 12 months (Figure 24) show changes in these scores between telehealth and standard home care are not statistically significantly different.

Two studies (McDowell et al 2014 and Lewis et al 2011) used SGRC and these were combined in sensitivity analysis to assess disease specific outcomes for COPD patients only. These results were highly heterogeneous (85%).

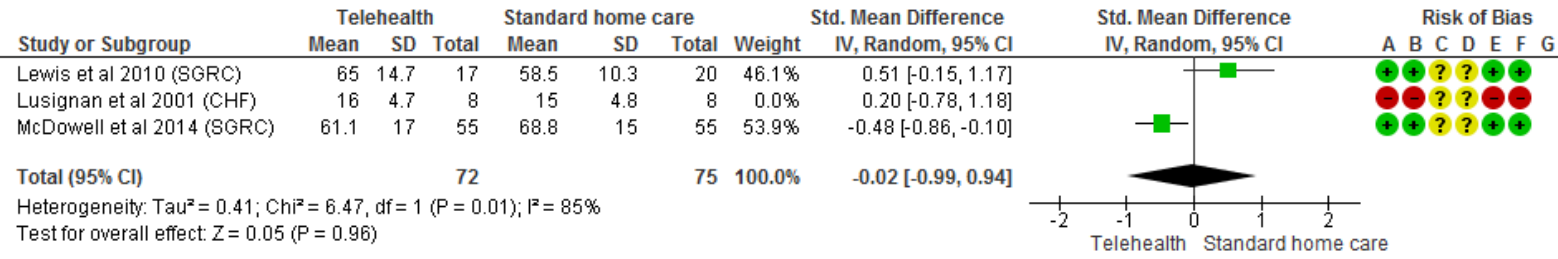
The minimal change effect size means the difference between telehealth and standard home care for disease specific outcomes is not clinically meaningful.

Figure 22: Disease specific outcomes at 6 months



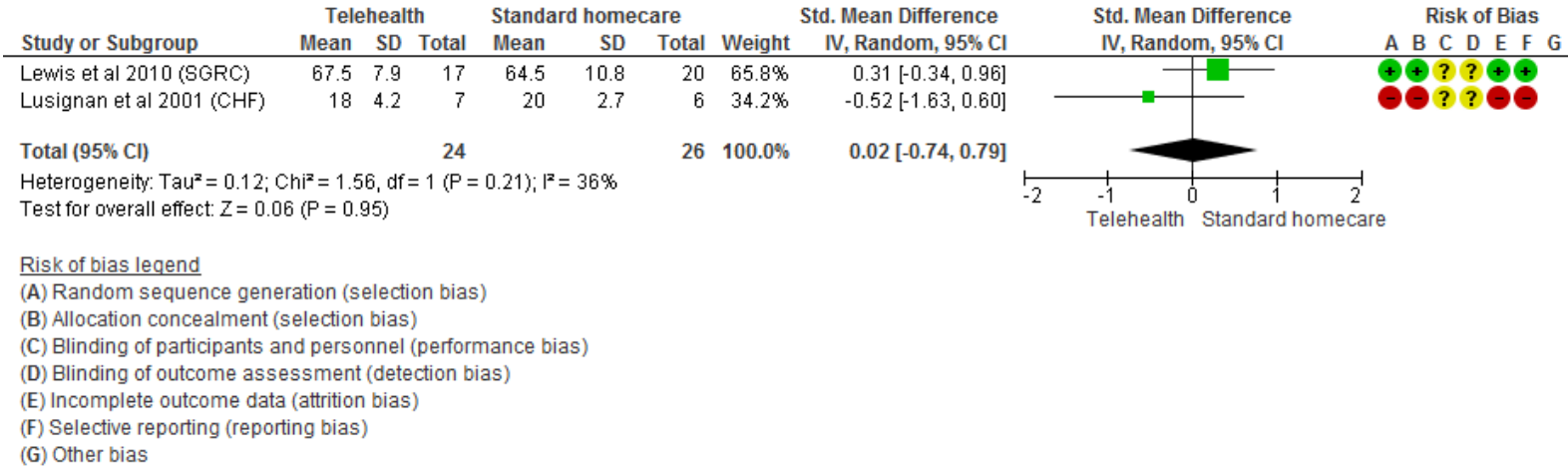
Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 23: Sensitivity analysis for Disease specific outcomes at 6 months follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

Figure 24: Disease specific outcomes at 12 months follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

2.4.15 Cost-utility analysis

One study reported on quality of life in terms of Quality Adjusted Life Years (QALYs) (Henderson et al 2013). QALY's for usual care group was 0.55 compared to 0.56 for telehealth. The cost associated with this was £5559 and £6384 for usual care and telehealth groups respectively.

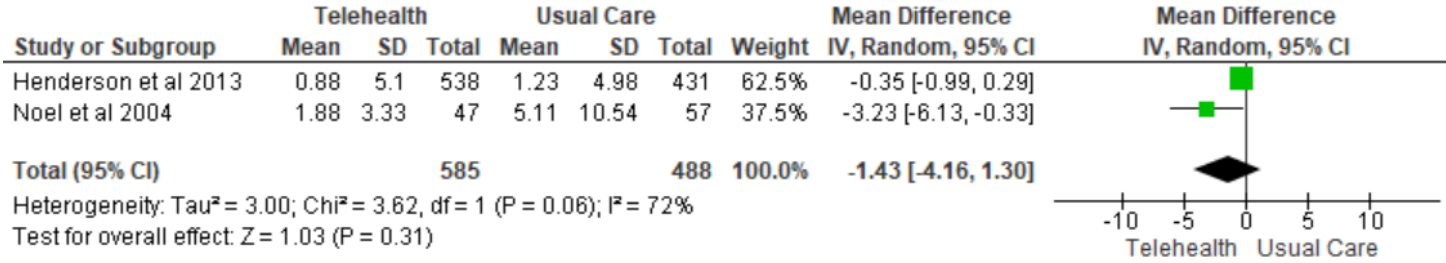
2.4.16 Inpatient bed days of care

Noel et al (2004) reported the difference in bed days of care (BDOC). At 6 months, telehealth group had reduced from 12.2 to 1.9 (SD 3.3) whereas control group BDOC decreased from 13.8 to 5.1 (SD 10.5).

Henderson et al (2013) who reported inpatient bed days at 12-month follow up were 1.2 (SE 0.2) for usual care group and 1.0 (SE 0.2) for telehealth group.

Figure 25 presents a meta-analysis combining the above studies and found no statistically significant mean difference between telehealth and usual care group for bed days of care.

Figure 25: Bed days of care at 6 and 12 months follow up



Risk of bias legend
(A) Random sequence generation (selection bias)
(B) Allocation concealment (selection bias)
(C) Blinding of participants and personnel (performance bias)
(D) Blinding of outcome assessment (detection bias)
(E) Incomplete outcome data (attrition bias)
(F) Selective reporting (reporting bias)
(G) Other bias

2.4.17 Qualitative findings

Two qualitative papers explored the effect of using telehealth on quality of life (Gale and Sultan 2012; Gorst, Coates and Armitage 2015). Both papers reported on adult COPD participants and overall study characteristics and intervention context were similar to those of included quantitative studies. Thematic synthesis of both qualitative papers enabled the development of 4 summative themes as discussed below.

2.4.17.1 *Telehealth provides peace of mind*

Telehealth provides peace of mind and reassurance for the patient and their family results from qualitative papers illustrated this as shown by the following quotes

"I just find it reassuring that I can check manually what my oxygen levels are, because I'm aware of the fact I get anxious about things… "they [family] are very much aware of the fact that I do not look after myself and so it reduces worry for them."

"I'd go so far as to say if I could afford it, I'd buy my own equipment and this peace of mind syndrome, it relaxes you a lot." Part of this peace of mind came from managing feelings of isolation and helplessness:

"know there's someone at the end of the line that can help me." "reassuring, it's like having another person with you even though it's a machine."

Which reduced the need for help form healthcare professionals:

"I haven't called them out so often [district nurses] since I've had the telehealth" reported

2.4.17.2 *Telehealth improves healthcare accessibility as people feel less of a burden*

Patients found telehealth facilitated 'better access to healthcare professionals'. Having the ability to remotely send in vital sign data because it meant that "you're not overlooked" and if you need a healthcare professional to contact you "they're straight onto it." This was valued by both patients and their carers and led a feeling of 'enhanced active engagement' in healthcare.

Telehealth also facilitated access to healthcare by legitimizing contact and 'ensured that nurses telephoned or made a visit when they were really needed.' This encouraged patients to engage with telehealth and provided relief of the sense of being a burden to health services. Patients who expressed a fear 'that they will waste their time' was overcome via telehealth which enabled visits to be made 'when they were really needed.'

Legitimized contact and access to healthcare was reported to have an impact on early identification of symptoms and early intervention. Telehealth was described as "it's sort of a lifeline" because "knowing that somebody is at the end of the line, that important" and "I think I would have been in hospital without it." Telehealth meant patients who previously rarely sought medical advice due to not believing their were "ill enough to warrant treatment" began to act upon symptoms because they were able to "readily ascertain whether there is a problem" and seek help accordingly (Gorst, Coates and Armitage 2015).

In terms of human resources, this factor highlights the potential telehealth has for patients to be triaged appropriately, whilst enabling them access and reassurance.

2.4.17.3 *Telehealth promotes ownership and self-management*

Patients felt more confident to self-manage their condition because telehealth enhances "aware[ness] of what is happening". "I seem to be eating a lot better" and went on to explain "It could be that I've got my confidence back" which demonstrates a positive engagement with telehealth.

Self-management and improved engagement with their condition and health was expressed by most participants. Improved awareness "definitely helped with health management" and made patients more engaged with their condition "I want to know about my health now." Prior to using telehealth, people were of the opinion 'that [the] community matron was responsible for looking after [them]" and so they previously "did nothing to manage [their] own health condition."

Telehealth empowered participants to feel "more self-sufficient" and some resulted in purchasing their own equipment.

2.4.17.4 *Fear of reduced face to face contact and isolation*

Disadvantages of telehealth were reported. Results discuss the impact telehealth has on limiting face to face contact for patients who may not have any other visitors. "The only thing I miss with it [telehealth] is that I do not get the nurses coming to visit like I used to, human contact" however participants did acknowledge "the nurse side of it is not necessary, there's no point having an nurse when they're only going to do exactly what you can do yourself" but "it's nice to have someone to speak to occasionally."

One participant from the qualitative studies provided an alternate opinion, not to be overlooked and explained a 'sense of restriction and invasion of medical technologies into their lives' which felt like being a "dog on a lead." This is significant when considering the practicalities and psychological barriers to acceptance and adherence to telehealth as a management intervention for people living in their own home.

2.4.18 Synthesis of quantitative and qualitative results

Quantitative findings reflected no statistically significant difference between telehealth and usual home care in terms of psychological well-being; anxiety and depression (refer to Section 2.4.10). Qualitative findings however reflect that patients did value telehealth and gained 'peace of mind' from its installation as well as experienced 'better access' and improved 'active engagement' with healthcare professionals due to 'legitimized contact.'

Despite meta-analyses representing a larger sample size and pooled sufficiently similar data, we recognise its limitations in terms of drop out rated and varying methodological rigour. In terms of psychological wellbeing, the qualitative findings are useful for presenting the patient voice that maybe masked in our non-statistically significant meta-analysis.

Bed days of care was not statistically significantly different between participant groups however in both qualitative papers were found to favour those people with telehealth. The explanation for such a result is that telehealth facilitates self-monitoring and self-management which enables patients to seek help when they need it rather than allowing their symptoms to deteriorate for fear of being a burden.

2.5 Discussion

The purpose of this systematic review was to identify whether telehealth is a useful intervention for home care patients with long term conditions. The primary outcome of interest was quality of life due to the existing evidence of strong correlation between diagnosis of chronic condition and poor psychological wellbeing which can have an impact on nutritional status.

There was no statistically significant difference between telehealth and standard home care. This was found in terms of quality of life, psychological wellbeing, physical function, anxiety, depression disease specific outcomes or bed days of care at 3, 6, 9 and 12- month intervals.

Cost-utility was calculated using QALY's in only one paper. The difference in QALY's between intervention arms were negligible at 0.549 and 0.564 for standard home care and telehealth respectively. As this was the only study to report QALY's as an outcome it is difficult to interpret it as a definitive finding.

Qualitative findings from 2 papers were predominantly positive about telehealth. Recurring themes suggest telehealth provides peace of mind, increases access to healthcare improves ownership and self-management. However, for some, negative aspects of less personal contact and invasiveness were voiced.

2.5.1 Strengths and limitations

2.5.1.1 *Rigorous methodology*

This systematic review followed Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 27-item checklist (Moher et al 2009). The search strategy used within this review was formulated and practised alongside the support of a subject expert librarian. MeSH terms and keywords were used as well as truncation terms. The inclusion and exclusion criteria for this review were concise with clear, agreed definitions reducing risk of ambiguity and uncertainty.

2.5.1.2 *General limitations*

The limitations of this review are largely consequences of the quality of included studies. Sample sizes of included studies were mainly small except from the Whole Systems Demonstrator trial and high drop-out rates were common in all quantitative studies. Common reasons for were funding, lack of participant acceptance of the technology, hospitalisation and mortality. To limit the impact on reliability of results, data were combined in sub analysis and reported separately. Heterogeneity among available quantitative study design, sample size and diagnosis of participants, follow up time and drop-out rates also made conclusions difficult. Most results reflect telehealth use and impact over a short period of time (6 to 12 months) rather than providing a true reflection of its long-term use.

Random-effects model was used in the meta-analyses of this paper. This method has known limitations which include overestimation of effect size and wider confidence intervals, but it was more appropriate than fixed effects given differences between interventions.

Only one researcher was responsible for the search strategy and decision over inclusion and exclusion of papers. However, to minimise selection bias, the search strategy was checked and approved by two members of the supervisory team; and final papers for inclusion were agreed with one supervisor.

2.5.1.3 *Potential publication bias*

No language restriction was used when carrying out the search strategy for this review. Despite that, all included papers in this review were in English language. There is recognition and discussion of editorial bias whereby papers published in English language are more likely to report positive results (Matias-Guiu & Carcia-Ramon (2010).. Here, this is noted as a potential limitation to this study. Searches using non-English language scientific databases were not conducted. Databases to search for grey literature were also not included in the search strategy, which does pose risk of publication bias. Nonetheless, to our knowledge this is

the first review attempting to pool and summarise results on the added value of a specific telehealth in long-term conditions.

2.5.2 Generalisability and applicability

The inclusion criteria were broad to ensure maximum generalisability and transferability of the findings, however included papers were from economically developed countries and predominantly reported on the UK population. Nonetheless, included studies had the demographic and medical context which is reflective of the highest proportion of long-term condition prevalence globally as well as in the UK. Participants in this review were adults with a mean age of 71 (49-90). In context, this population are responsible for £5 billion annual cost to the healthcare system and is projected to continue to increase by a further £5 billion by 2020, which outstrips healthcare resources. Our review suggests telehealth offers peace of mind, promotes self-management and more appropriate access to healthcare.

2.5.3 Consistency of findings

This is the first review attempting to pool and summarise results on the added value of telehealth, specifically defined as the exchange of medical information between a service user and healthcare professional, in long-term conditions. A review of randomised controlled trials investigating telemedicine in broader terms; to include video-conferencing, remote monitoring, education and real-time assessment of clinical status, found disease specific quality of life improved more for heart failure patients receiving telemedicine than usual care (Mean difference in Minnesota Living with Heart Failure Questionnaire (MLHFQ): -4.39 95% CI [- 7.94, -0.83] (N=482, 5 studies). And like our results, no difference was found in hospital stay. With pooling results from multiple technologies, it is difficult to tease out which type is responsible for changes in outcomes and

the ineffectiveness of one technology could be masking the effectiveness of another, so the applicability of such findings are limited.

2.6 Conclusions

Quantitatively telehealth is not statistically significantly different to usual care for changes in quality of life, psychological wellbeing, physical function, anxiety, depression, disease specific outcomes or bed days of care at 3, 6, 9 and 12 month intervals. Qualitative findings suggest important benefits to patient's peace of mind and confidence to access healthcare appropriately.

The null effect of quantitative results does not mean we should rule out telehealth within this population group and context. Instead, identifies more research is required. When compared to qualitative results and the difference of opinion of telehealth highlighted, this study is an exemplar that in health and care choices, one size does not fit all and care management should be tailored by informed choices made by the patient and healthcare professionals.

2.7 Implications of results from systematic review and meta-analysis: what does this mean for further research?

Findings presented in this paper are useful for providing an overview of the current evidence base of technology use in home care patients with long term conditions and its potential to impact quality of life. However, high quality randomised controlled trials are needed which are specific to a technological intervention and disease state for results to be clinically meaningful and truly reflective of usability and impact.

Before being able to go on and attempt to solve malnutrition in this setting with a technological solution, I needed to understand nutritional practices within this setting and better understand the barriers to achieving nutritional wellbeing.

The lack of documented nutritional insight in this context and setting means I needed to go into the field and formulate understanding. Depth and value were obtained through speaking to different stakeholders (service users, carers, nurses and care managers) and observing and reflecting on the current nutritional practices within the private home care setting.

3 Ethnographic methods

3.1 Introduction to Chapter 3

The findings of my systematic review highlighted that nutrition was not a priority and seldom reported on as an outcome in this context. I therefore conducted an ethnographic, exploratory study to provide a basis of insight and understanding of nutrition within this population, context and setting.

This chapter aims to build on Chapter 2, where I introduced the concept and fundamentals of ethnographic research and its use within healthcare research. Here I provide a brief reminder of the main principles of ethnography and justify its use in attempt to answer my research question. In this Chapter I introduce CareCo Healthcare as an organisation as well as a private care provider and provide context for health and social care as a workforce. I then go on to explain the process of recruiting participants, my inclusion and exclusion criteria and data collection and analysis methods.

3.2 Research question, aims and objectives

3.2.1 Objective

This study design seeks to understand how nutrition is managed within the homecare setting for people with long term conditions through in-depth focus on a small sample and produce narratives and knowledge based on participatory observations, insight, and reflections.

3.2.2 Aims

I set out to understand the knowledge, perceptions and attitudes of malnutrition in people who have long term conditions from the service user, carer and care provider perspective, and why this is still such a prominent issue in people who receive long term home care. I aim to understand the experiences of service users to

understand their stories, barriers and facilitators to good nutrition and hydration and, indeed, whether they considered it to be a priority. I also aim to improve understanding of the roles of carers and the barriers and facilitators to supporting nutrition and hydration from their perspective as well as that of the care leaders.

3.2.3 Research questions

1) How is nutrition managed within the homecare setting in people with long term conditions?
2) Are there barriers to optimising nutritional wellbeing within this setting, from the service user, carer or nurse and care provider perspective?
3) Are there any facilitators to optimising nutritional wellbeing within this setting, from the service user, carer or nurse and care provider perspective?

3.3 Study design

As previously mentioned, there is no clear definition for ethnography, rather a range of principles which help us to establish what it is and rule out what it is not. The lack of a clear definition does not diminish its value as a research methodology; rather enables flexibility and means this approach is amenable to a range of settings and nuances (Hammersley and Atkinson 2007).

Ethnography refers to the study of a phenomena within a particular context and setting. Its aim is to understand people through study of people, actions and accounts in naturally occurring contexts as supposed to experimental or highly structured settings.

3.4 Study setting

3.4.1 Who is CareCo?

Throughout this part of my thesis I will use a pseudonym for the care company I will be reporting on and refer to it as CareCo. Its true name has been protected for legal purposes. Any identifiable information will also be excluded.

Content removed to protect anonymity of company profiled

Content removed to protect anonymity of company profiled

3.4.2 Who are CareCo Healthcare?

CareCo Healthcare "provide care to clients at home through self-pay, personal health budgets, commissioned by the CCGs, local authorities and social services." CareCo Healthcare provide a range of services which include but are not limited to long term conditions, brain and spinal injury care, palliative care, hospital at home, live in care, holiday and event care, and social companionship.

CareCo Healthcare employees range from social support staff and companions, to care assistants and nurses who are trained to provide complex care. Latest published figures from 2018 show that they provide care for 2,900 adults and children in England, Wales and Scotland, which required a workforce of 1,500 care staff and 2,000,000 hours of complex care (low level care needs not included). Over the regions of the UK CareCo Healthcare operate, there are 15 regional branches that are responsible for providing a 24-hour telephone service for care staff and clients or relatives to contact (CareCo 2019). Each branch has an overall branch manager as well as senior nurses who are responsible for conducting initial assessments, bidding for new clients, writing care plans, overseeing recruitment and training and competencies of staff as well as ongoing reviews of care and dealing with conflicts or complaints.

CareCo Healthcare are regulated by the Care Quality Commission (CQC), who released a new approach to reviewing and enforcing care standards in 2015. The CQC publication explains they conduct comprehensive assessments of care quality based on five fundamental standards of care as follows; is it safe? Is it effective? Is it caring? Is it responsive? Is it well led? Inspections tend to occur over a 48-hour period by two inspectors who provide 24-hours' notice to the branch manager prior to their arrival. Inspectors use data and evidence from written care plans and record keeping and speak with clients and relatives to monitor whether the five fundamental standards are being achieved. Branches are then rated in each category as either inadequate, requiring improvement, good or outstanding. The outcome of these assessments determines the regularity of monitoring (CQC 2015).

Breaches of standards can see registration with the CQC being, dependent on the seriousness of the breach, whether there have been multiple or persistent breaches and this can lead to management review meetings, criminal enforcement or registration with the CQC being cancelled (CQC 2017).

3.4.2.1 *Context of care worker recruitment and retention*

Within this field, it is well known that care workers are often low paid and on minimum hour contracts. Statistics from the Adult Social Care Workforce Data Set (ASC-WDS) have been published and present data on the employment rates in the independent sector only (those employed in the NHS not included). The report showed an average of eight percent pay increase from 2012-2019, to £8.10 per hour. Forty-seven percent of people were employed full-time, and 24 percent of the entire workforce were on zero-hour contracts. However, for those employed in domiciliary care (otherwise referred to as home care, as within this research), the proportion of people on zero-hour contracts was between 43 and 58 percent (Skills for care 2019).

Last year, there were 440,000 leavers (30.8 percent) in the preceding 12 months and yet 66 percent of workers remained in the sector. The size of the workforce had grown by 22 percent in the last decade, however, the increase of employment had slowed within recent years to 0.5 percent growth. At any given time, this report shows there are 122,000 vacancies. The 2019 report highlights that the region in which this study was conducted has the highest rate of workforce vacancy within England, at 9.3 percent, compared to the national average of 7.5 percent (Skills for care 2019).

The worsening patterns I present here are not unique to this field, instead they reflect national statistics of staff shortages and cost burdens across all health and social care. A 2019 report from The Health Foundation present '*Priorities for the next government'*. Within this document, the challenges we are experiencing within health and social care workforce are discussed in relation to the compromise on patient care. In order to provide high quality care, the skills and training of the right professionals are needed at the right place and time, however staff employment cannot meet the ever increasing demand, increasing pressure whilst rate of pay in restricted by burdening financial constraints (Gershlick and Charlesworth 2019). If we consider these

challenges and partner them with the fact that nutrition is a low priority in terms of policy, it begins to provide potential explanations for why malnutrition remains such a significant issue within the UK.

In the initial phases of my research, I was able to spend time at CareCo Healthcare head office and the managers there informed me that staff turnover was over 40%, which was a particular challenge the organisation was continually trying to overcome. My time at CareCo Healthcare head office was insightful, providing me with a better understanding of the operations and logistics of running a healthcare service in the private domain. During the days I spent there I also learned to appreciate the financial and political constraints which tie into health service provision in terms of funding differences which occur between boroughs and how that directly impacts health inequity as people are not able to access particular services due to their location.

3.4.2.2 *How are new clients won and care plans agreed?*

In private home care provision, cases go out to tender that a company bids for based on quality of care, reputation, and projected cost. Winning long term care packages secures future income, which means it is competitive business.

Initial assessments are conducted by a case manager, NHS trust or home assessments are conducted by a community nurse. These initial assessments combine medical and social assessments from documents as well as through meeting with the potential new client, and relatives or others in that specific household, if appropriate. The medical and social assessment is developed through meetings and conversations so that CareCo Healthcare can gauge what are the persons needs and priorities to devise an appropriate care plan. Where a person has reduced mental capacity, a health advocate may be sought upon in best interest.

Next, once the client is ‘won’, a care plan is written and recruitment begins to recruit care staff and train them with specific skills and knowledge to match the client needs and care plan.

From my time with CareCo Healthcare staff and leads I understand the criteria for recruiting a carer is as follows:

- Minimum 6 months experience
- CQC Level 2- Basic care
- Telephone screening
- Mandatory online training- (this does include food hygiene)
- Would hold a day which is set up to cater to for the upcoming clients needs
- Potentially go onto training day where the candidates are observed by staff to see their engagement/ personality traits
- Successful candidates will do a meet and greet with the client and/or family
- Shadow shifts in hospital or community with current care team
- 2-3 days with nurse and the client to be signed off for competencies which include record keeping, medications, manual handling, pressure ulcers

Once there is a pool of potential staff for the care package and observations have taken place by case managers, a “meet and greet” occurs, where the client will then decide which care staff they feel most appropriate.

Reflecting on this process, it seems very much from the commencement of the care package, the client is the authoritative figure and able to choose their care staff. This was a significant learning curve for me and distinguishes some of the differences between public and private care. Funded or private care seems slightly more transactional compared to public care, in that service users decide all of their care, compared to the public sector when a patient is typically referred and assigned to a clinician. I do not wish to overstate this, as patients within the NHS express preference for clinicians, and it is gold standard for patient centred care to always be the centre point of care planning and delivery (Royal College of Nursing 2020).

3.5 Participants

3.5.1 Inclusion and exclusion criteria

Please see Table 3 below for details of the inclusion and exclusion criteria adopted for recruitment in this study.

	Inclusion Criteria	Exclusion Criteria
Client	• Aged 18 years or over • Currently receiving home care from CareCo Healthcare • able to provide informed consent • confirmed diagnosis of a long-term condition, or providing informal care for someone who does • able to communicate • able to provide informed consent	• under the age of 18 years • under palliative or end of life care • assessed to not have mental capacity • not currently receiving home care from CareCo Healthcare • no confirmed diagnosis of a long-term condition • unable to communicate • unable to provide informed consent
Informal carer of client	• Aged 18 years or over • Providing informal care for a CareCo Healthcare client who has a diagnosis of a long term condition •	• under the age of 18 years • not currently caring for someone receiving home care from CareCo Healthcare • unable to communicate • unable to provide informed consent
CareCo carer	• Employee of CareCo Healthcare • Assigned to a package of care with a client who meets the inclusion criteria (care staff, nurse or manager) • Willing and able to provide informed consent	• Not employed by CareCo Healthcare • Not a carer for CareCo • Unable to or unwilling to participate or provide informed consent
Senior CareCo staff	• Employee of CareCo Healthcare • Assigned to a package of care with a client who meets the inclusion criteria (nurse or manager) • Willing and able to provide informed consent	• Not employed by CareCo Healthcare • Not a registered nurse or branch manager at CareCo • Unable to or unwilling to participate or provide informed consent

3.5.2 Participant Recruitment

Qualitative research generally uses non-probability sampling, which lends itself to not seeking generalisability as an outcome. Instead, it prioritises seeking information-rich data that is phenomena, context and setting specific. Common critique of qualitative research's lack of usefulness and transparency in comparison to its quantitative counterpart can be lessened through clear explanation of the sampling and recruitment process, which is what I aim to provide here (Higginbottom, Boadu & Pillay 2013).

Ideally for healthcare research, representative sampling would have been used in order to have representation from each clinical condition group that CareCo Healthcare care for so that, in essence, it would be reflective of the context. This can be true specifically within healthcare research given economic and time constraints of healthcare funding. Representative sampling can be useful for identifying specific patients with a specific condition or experience to ensure variation in phenomena presented (Miles and Huberman 1994; Atkinson and Hammersley 1998).

In focussed ethnography, the most commonly documented technique to recruit a sample is purposive sampling, in that participants are specifically selected based on their knowledge, experience or insight as this qualitative research tends to lend itself to tighter constraints in terms of time, funding and resources (Crookes & Davies, 1980).

Initially, for reasons explained above, I requested a breakdown of the adult care provided including which conditions they had so that I would be able to aim for a representative sample that reflected the demographic CareCo Healthcare care for. Unfortunately, I was informed that this information was not available and no central database like this existed. For a large organisation, I found this slightly obscure given that in clinical care I have always experienced databases and spreadsheets that clearly document overall caseloads, as well as both active and discharged patients.

Nonetheless, I needed to still be able to recruit participants and so I needed to be flexible and go with what was available to lead my line of enquiry. As such, I was partnered with a specific CareCo Healthcare branch and, from there, was able to contact the leads at that branch to set up initial meetings. It took several meetings

and email correspondence for us to build a working relationship and for them to gauge what this project was about and begin to build working relationships. I expand on the impact this had on data collection and analysis later in my results section, Chapter 4.

A meeting was held with myself, two senior nurses and the branch manager and we discussed the project and more specifically my inclusion and exclusion criteria. From here, the staff discussed various clients on their caseload who may be of interest and who may be willing to participate in a research project, as well as be able to provide consent. Therefore, in the end, my participants were a purposive sample, specifically identified and approached due to their specific condition, experience, knowledge, or expressed interest in participating.

Given that I have had no prior relationship, knowledge or experience of CareCo Healthcare and the clients that they provide care for, selection of potentially relevant participants was completely dependent on their suggestion and power as gatekeepers to recruit. The idea that there is an inextricable intertwining relationship and interplay of knowledge and power, particularly how this occurs in participatory research, is interesting to consider and explore here (Gaventa and Cornwall cited in Reason and Bradbury 2013).

The extent of which CareCo Healthcare asserted power due to knowledge of their client base will have shaped my research project and will have shaped my line of enquiry and findings of this project. The absence of potentially relevant and insightful voices within a research process is explored by Lukes 2005, who questions whether this should be interpreted as own inefficacy or because of the political influence from those with "more" power. I do not wish to exaggerate this phenomenon, but I feel it is an important point to consider to an extent (Lukes 2005).

Typically, in qualitative research, one would rely on data saturation to dictate and justify sample size and seizing data collection (Guest, Bunce and Johnson 2006). For this project, data saturation was not desired, nor possible given the nature of it being exploratory research, augmented by the diverse experiences and nature of participants both sought after and available. Time and resource constraints also played a role in deciding participant size given that I am an independent researcher, undertaking a PhD project.

3.6 Ethics

This research was granted ethical approval from CU Ethics at Coventry University (see Appendix 1).

3.7 Data Collection

A gatekeeper agreement was signed between myself and the Chief Nurse at CareCo Healthcare. This document helped to ensure recruitment of key informants "who possess particular knowledge, status or communicative skills and who are willing to share that with the researcher" (Zeldtich 1962). Key informants may also be chosen if they are atypical, owing to the fact they may have differing experiences to allow for a purposive, representative sample for data collection (Dean 1967).

Once potential key informants – also referred to as participants – were identified, participant information sheets were distributed to care staff and service users, including branch nurses and managers. These are detailed in Appendix 2 and 3, respectively. The participant information sheets outline contact details for the principle investigator, should participants want to get in touch for any additional information.

Informed consent forms were obtained from branch managers and nurses at the initial meetings where potential service users who met inclusion criteria were identified and discussed. CareCo Healthcare managers contacted the identified service users and their key care workers to gain verbal consent to participate prior to meeting the researcher or at the beginning of the initial meeting with me, at which time written informed consent was gained. Every participant was provided the opportunity to ask questions prior to consenting to participate and was made aware of their rights to withdraw from the study. Appendix 4 and 5 outline the informed consent forms for staff and services users.

Through participatory observation, the researcher acted as both an active participant and researcher simultaneously. The tradition within ethnography is therefore that the researcher allows for a period of rapport building, a time to become acquainted with participants prior to beginning data collection, also referred to as "mapping" (Schatzman & Strauss 1973). Factors such as age, gender, sexuality, culture, ethnicity and

socioeconomic status differences between the researcher and participants could hinder or facilitate data collection. Hence, this is a fundamental stage in ethnographic research.

In line with ethnographic methods, participants were not formally interviewed, instead informal "conversations with a purpose" were held with care staff and service users and care provider managers (Burgress 1984). The purpose of these were to try and elicit true accounts through flexibility and openness to conversations. Conversations were not audiotaped, unlike other qualitative methods that advocate this as a method to show validity. In fact, with ethnography it is recognised camera or tape recordings of participants can be counterproductive, hindering the "natural" conversation and behaviour and in turn reducing the validity of the research (Le Compte & Goetz 1982).

This study is an initial exploration of current practice and perceptions of those whose lives are affected by either having a long-term condition or caring for someone with one. As such, the nature of ethnography enables insight into the population in a context, setting specific way to collect data not only through conversations but triangulated by observation and reflection to construct knowledge and understanding which is currently lacking. Use of other qualitative methods such as formal interviewing alone would therefore not provide this opportunity.

Much like in other qualitative work, non-verbal cues would be expected in the presentation of data, there is suggestion of what to report on in ethnography to improve transparency for the reader. Space, people involved, activity, objects present, actions, events, time sequencing, goal that people are trying to accomplish and feelings or emotions should be documented by the researcher (Roger, Kuper and Hodges 2008). Due to the "natural" nature of data collection through informal conversations, documentation of these aspects is viewed as a method of eliciting highly reflective accounts from participants (Roger, Kuper and Hodges 2008).

Conversations with care staff that involved confidential service user information were held in the service users' homes, and at the CareCo Healthcare branch. More general conversations regarding long term home care and service provision occurred while travelling to or from meetings and over drink or meal breaks. All conversations with service users took place in the service users' own homes by one independent researcher,

excluding one participant who was visited during this long stay at hospital for several hours. Topic guides for care staff and patients can be found in Appendices 6 and 7 respectively.

Meaningful conversations helped to validate observations through incorporation of open-ended and closed questions, which provided insight to participant feelings and how and where they perceived value in their lives (Roper and Shapira 2000). Transitioning from general to specific questioning where it was appropriate within the conversation through use of probes such as “are you able to tell me a bit more about that?” enabled depth of understanding (Higginbottom, Boadu & Pillay 2013).

Meetings with the researcher took place for 40-150 minutes. All conversations with service users took place in the comfort of their home excluding one, who was in hospital at the time of the study and consented to meet with the researcher there. Conversations with service users took place in the presence of their main carer or nurse and all but 2 service users were seen with a branch manager from CareCo Healthcare present.

A participant-as-observer overt approach to data collection was adhered to throughout this project so that participants were able to provide informed consent to participating. This method of data collection allowed me to immerse myself in the study context and collect observations, field notes and reflections to help develop the understanding of lived experience. I tried to use an emic approach to data collection throughout in order to feel immersed within the culture and lives of participants to observe and understand their ways of life and activities.

My observations and reflections of my time with the company, staff, carers and service users I will also be considering as data and I will draw on these in more detail in my results in Chapter 4.

3.8 Data analysis

Unlike other research designs, data collection and data analysis in ethnography are not two distinct phases, instead they occur simultaneously to allow data analysis to drive further data collection (O’Reilly 2012). Reflections of observations as well as of accounts given by care managers, care staff and service users

occurred whilst I was in the field from initially collecting data from service users and coming away to discuss with the care provider. This helped – at times – to triangulate findings whilst other times, made room for further self-reflection. Reflections were ongoing, from initial collection to months and weeks after coming away from the field as I developed my findings and write up.

Continuous analysis and reflection occurred using a three-stage model. Deconstruction (known otherwise as open coding) seeking to expose the constructs which have been observed; Construction (axial coding) seeking to meaning-make or theorise the phenomena found; and Confirmation (selective coding) data is used to document and present the developed theory (Strauss and Corbin 1990 cited in Pielstick 1998).

This process is not very dissimilar to thematic analysis in the sense it allows for theory generation and development, however, it enabled me to theorise my reflections and continuously check and modify them to ensure a true recount of people's perceptions alongside. This was really crucial given that I had initially anticipated there being time to conduct return visits, which in the end was not possible.

Continuous reflection since my time in the field has occurred through reading and re-reading my field notes and observations as well as considering how I felt throughout that time. This has led to a depth of meaning making, reflecting on power and knowledge interplay and how I, as a research tool, have impacted data as well as how I view and interpret it. In the next Chapter I have incorporated these reflections throughout the presentation of results. In Chapter 4 also reflect on positionality prior to presenting results as this is one way to ensure rigor and quality in ethnographic research (Higginbottom, Boadu, Pillay 2013).

3.9 Epistemological considerations and the impact of the researcher on research

Epistemological concerns within the process of social science and indeed, ethnography is unavoidable. I will here explore issues around identity and knowledge to consider how these may have shaped my data collection and analysis. I also build on these concepts later in Chapter 5 through discussion of theory and my results.

Social identity has been broadly described as knowing who we are and who others are. Identification is internally orientated meanwhile classification is externally judged by others, based on interpretation of identity. From a sociocultural perspective, identity is in continual negotiation with practice and may be the formation of multiple interconnected trajectories related to affiliation with various communities (Wenger 1998). Hence, all human knowledge and knowledge exchange is dependent on social identity, interpretation and engagement (Jenkins 2000). For my research, this means to gain insight into field of home care and people with long term conditions, I first need to explore my identity, how I perceive others and how I am perceived by others.

Firstly, CareCo Healthcare know that I am a dietitian, which holds a range of connotations in terms of being a healthcare professional and having specialist knowledge. My experience working within the healthcare setting, within the community and communication with patients, relatives and multi-disciplinary teams is likely to frame my interaction with all participants.

My interaction with care staff and nurses I expect may be comparable to a work relationship. I hope that my identity allows me to be perceived as a caring, trustworthy individual. Ideally, this would allow for more open conversation and participants to feel there is a safe philosophical space to speak freely, which would provide a deeper degree of meaning making and construction of knowledge.

On the contrary, I need to acknowledge that my role and identity as someone external from CareCo Healthcare and being funded may lead to questions of my identity and how I am perceived by participants. This could be unhelpful to data collection if there are concerns of my intentions and so I will need to build rapport and ensure participants are aware of anonymity and confidentiality when they are providing consent to participate. However, reaffirming my role as a researcher to participants creates its own set of challenges within this study design for this study design, as it negates from the naturalist paradigm ethnography aspires for.

Clarifying my role to myself is something I will need to do continuously throughout my time in the field to ensure I refrain from sinking into my dietitian role or leading discussion. I will need to clarify my role to

participants also and be prepared to navigate conversation away from nutritional assessment or advice giving which I expect may be challenging.

Work from Cotterill and Letherby (1993) support that research-researcher relationships are not one dimensional, nor are they unidirectional. Instead the engagement between the researched and researcher will impact the personal and intellectual nuances within both parties (Letherby 2002). I will therefore need to consider this and include reflective narratives of my identity and role throughout my time in the field and the influence that has on my data, analysis and interpretations.

My clinician-researcher role presents risk to the data collection and analysis process which is unavoidable and needs to be managed accordingly. My previous experience of working within healthcare and meeting people in their homes may mean that I assume I have knowledge within this context. There is a risk therefore, that I may sense familiarities between my experience and current time in the field which could subsequently lead to me not documenting all data. Being that the context, phenomena and my purpose for being within the field are very different to my previous experience, I need to proceed with caution and I document as much data as I can, ensuring I note and reflect continuously.

I agree that there should be no hierarchical difference between myself as the researcher and those who are being researched. However, it is important to question the impact that my status as a dietitian and an external person, funded by CareCo Healthcare had on the all participants, whether that be the service users or carers, nurses or managers.

4 Results of ethnographic exploration

4.1 Introduction to Chapter 4

Throughout this chapter, I will present the results of my research. Prior to presenting results I explore who I am and how my role as a researcher and as a research tool may have shaped data collection, data analysis and subsequently, the results I present in this chapter. I explore positionality and present a Venn diagram of what makes me, me and how that could have shaped this research project. I present results through case studies which start with a list of condition and care package characteristics to maintain anonymity but also to provide context for each case. You will find throughout each case study that I have included context, primary quotes from participants, observations, reflections, and discussion of their care plans. After each set of results, I summarise key findings which I then combine to compare and contrast at the end of the chapter, finishing with a personal reflection of my time in the field.

Throughout this chapter I pose questions in each case study which I reflected on throughout my time in the field or since leaving the field. I go on to elaborate and explore the questions raised in this Chapter in more depth in my discussion in Chapter 5.

4.2 Reflexive account: Myself as an ethnographer

I am a white middle-class young woman. I was always interested in food technology and sciences at school but became interested in Dietetics when both my grandfathers suffered from ill health. One was diagnosed with Alzheimer's and his condition caused his nutritional intake to change at each phase as his disease progressed and his functional and cognitive ability declined. His weight declined dramatically throughout his pacing phase and this seemed to worsen his condition as he was soon needing to be fed and reliant on oral nutritional supplementation. My grandad who had suffered a cerebrovascular attack became reliant on home care to prepare his meals, assist with personal hygiene, and allowed him to have some human interaction on

days we were unable to visit. His care visits were time limited and focussed mainly on personal care and transferring him from bed to a chair or commode. His nutritional options were limited due to his reliance on carers who were not able to use the oven, often meaning he was reliant on cereal or a sandwich during the day. Before long he began to lose weight and had visible muscle wasting in his arms and legs, which then made it more difficult for him to stand long enough to transfer on a turner. Both relatives had unmet nutritional need along with modifiable lifestyle behaviours which could have prevented illness later in life and it was at this time I was guided to study Dietetics.

Since qualifying as a registered dietitian, my role has provided me with experience as both a community and acute dietitian. As a community dietitian I have been exposed to peoples' lives and providing tailored care based on personal preferences lifestyle behaviours. My role as an acute dietitian has developed my skills, awareness and understanding of the healthcare system and transition from primary to tertiary care and the difficulties that can arise with continuity of care and accessing ongoing support for patients in the community. This aspect of my role has also made me aware of the number of people who are often discharged and readmitted to hospitals and appreciate that malnutrition is a significant underlying cause of hospitalisation, which is frequently undervalued, underestimated and under-researched in healthcare. This is reflected in the plethora of medical research where malnutrition is not considered.

Working as a community dietitian for the NHS, I have gained the communication skills of being able to do home visits and walk into a new and unknown environment to meet a new person and immediately build rapport. I have two years of experience developing these skills and, in many ways, conducting ethnographic research and meeting new service user participants relied on the communication and interpersonal skills I have developed throughout my role as a clinician.

Within the NHS, prior to my current role as a specialist community dietitian, I worked part-time as a long-term conditions dietitian where I provided dietetic assessment and care for patients with COPD, respiratory diseases and cardiac rehab/heart failure. Within my role I worked independently, conducting home visits to patients who were newly referred for dietetic assessment and review visits as well as having a clinic for patients who were able to get to clinic. I also worked within part of a wider multi-professional team comprised of nurses, physiotherapists, psychologist and an oxygen specialist to provide holistic care.

My clinical role within a specialist team, caring predominantly for severely chronically ill people in the community provided me with a wealth of experience in dealing with unknown circumstances in a professional manner. As healthcare professionals, we are trained to notice cues and explore those through open conversation with the patient and whoever may be present in their home in order to develop an understanding of how everyday life is for them and what their priorities are. Similarly, our dietetic training leads us to be inquisitive thinkers and analyse situations as we go in line with quality care guidelines and so that we are able to highlight potentially unsafe practice, safeguarding and areas for service improvement.

My ability to build rapport with patients has been a key skill which I have developed since my training began, throughout placements and now in my working life for the past two years. Being able to knock on the door of a stranger and build a good therapeutic relationship is something which has enabled me to work well with my patients toward shared goals and I am proud of my ability to do that and know that it has served me well in my professional life. This is a key skill that I have brought into my research and specifically suits ethnographic research methods and having meaningful conversations and purposeful interactions, meanwhile documenting notes and jottings. However, I am aware that although I have refined this skill within clinical practice, it would be an overstatement to portray that we capture everything. Indeed, through adopting the clinician-as-researcher role, I need to be cautious of the risk involved with politely disregarding facets which I deem irrelevant to my being there, which may be relevant to the participants and instead ensure I adopt a more open exploratory role.

Similarly, my note taking is a skill I have developed throughout my time as a community dietitian, as when you enter into someone's home there is usually a lot of other things going on, other people present and you need to adapt. This is in addition to being mindful of their environment and how that feeds into their daily life. Being able to take notes while maintaining conversation is something I have to do in my line of work as well as being able to ask open questions and not be afraid to ask someone to expand on their answer, picking up on verbal and non-verbal cues and building a detailed report or assessment from that.

Through this role I found that chronically ill patients have heightened anxiety, many are grieving their "normal" life and being able to go about their normal lives with their families. I now understand that this is a concept known as "anticipatory grief", which can extend to friends or family members of the diagnosed

person. Suicidal ideation was unfortunately rife in my experience of patients with severe COPD as quality of life was poor and the ability of carry out activities of daily living (ADLs) was very restricted, limiting independence. In the initial phases of this role I felt ill-equipped to enter into conversations of suicide with my patients, which led to feelings of guilt and apprehension that I was not fully supporting my patients. I therefore undertook a training course on how to manage suicidal patients; this provided me with better communication techniques, and the reassurance I needed, not be as nervous having these conversations.

4.3 Positionality

Determining methodological rigor in ethnographic research can be difficult. It has been well reported that a self-conscious, reflexive, and transparent approach to reporting can help to establish methodological rigor (Higginbottom, Boadu & Pillay 2013). For this reason, I have tried to be as reflexive and open as possible throughout this research.

During data collection and analysis, I was cautious to position myself closely with the data through active participation and engagement with participants. This enabled me to build good relationships with an element of trust and openness, which was important to obtain deeper insights and understanding of the participants. Making field notes and reflections began from my initial contact with the gatekeeper and allowed thorough and continuous documentation of the research journey which in turn has shaped project.

Throughout data collection, I made a conscious effort to maintain an analytical boundary, by questioning care practice and probing meaning to ensure I was not being presumptuous or being over-familiar with the context. This enabled me to remain detached enough for analytical interpretation to occur. As it is well documented, to

become comfortable with the uncomfortable or unknown is a dangerous position for the researcher to be and will result largely in presentation of superficial data (Loftland 1971 cited in Hammersley & Atkinson 2007).

I cannot avoid or detach myself from my identity as a clinician and the risk associated with predisposed ideations that entails, based on my clinical experiences to date. I too am aware that to strive for adoption of a "researcher" role too, poses risk to the naturalism which ethnographic research endeavours to achieve (Wells 2010). The issues of dual-identity and the impact this has on my research is explored in greater discussion in Chapter 5.

Figure 26 is a Venn diagram where I have tried to depict my positionality, to present myself as transparently as possible as a person. I have presented my previous knowledge, experience and values to show appreciation for the interplay that will have had on data collection throughout my project. I have included aspects ascribed characteristics and physical and social position which may have shaped my interaction with all participants throughout my project and the data I was able to collect. I have expanded on values from my professional training which I draw on in all engagement of patient care as well as everyday life and will have guided my interpretation of data, be apparent in my reflections and findings.

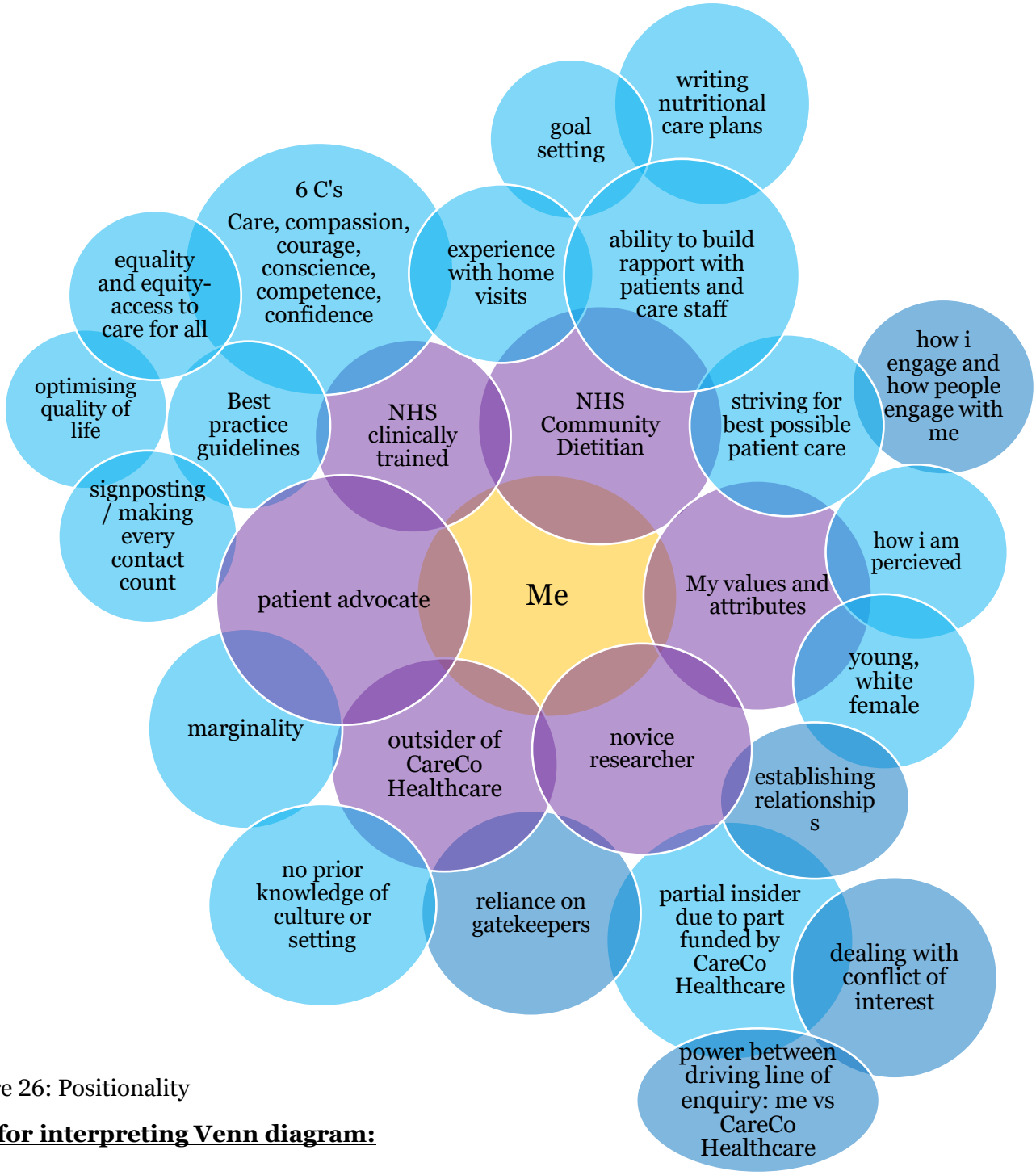


Figure 26: Positionality

Key for interpreting Venn diagram:

- Me: how I present as a person
- Key attributes or details of me which participants will know at face value
- My values, training, skills, and experiences which I have developed throughout my career and have shaped me as a person which I bring to my work
- Social interaction and unspoken challenges- pragmatics

4.4 Study demographic

In the interest of anonymity and confidentiality, specific details have been excluded in this report however, I here attempt to provide some context about the demographic in which my participants were pooled. This was a UK based project. The region in which my participants were recruited is one of the most ethnically and culturally diverse places worldwide, with over 300 languages spoken in this area.

This region has a whole has the biggest disparity of income within the whole of England, with the highest proportion of households in the top and bottoms tenth of national household incomes respectively. Overall, this area has the highest rate of income poverty in England. The specific area within this region whereby my participants were recruited have experienced some of the highest levels of growth in unemployment, poverty, homelessness, and ill-health in the country over recent years.

Despite the overview provided here presenting a rather bleak context the participants included in this research were very diverse in terms of their socio-economic status, ethnic background and level of education. Participants also differed in terms of how their care was funded, ranging from self-funded, NHS part funded and Clinical Commissioning Group (CCG) funded; there were also participants who had won clinical negligence court cases and been awarded funding for their care.

4.5 Study Participants

A total of 14 people participated in this study, a majority of whom were service users with a diagnosed long-term condition. Other participants included main carers, nurses and branch managers. A range of conditions were included. The length of time participants had received home care from CareCo Healthcare ranged from 1 to 8 years. The length of time CareCo Healthcare staff and carers had worked for CareCo Healthcare also varied greatly.

Care packages ranged from simple to complex care needs. Client's needs and care included in this project ranged from single person social care visits for several hours, multiple times per week to those who required double up, twenty-four-hour care.

I will now go on to present my findings as case studies which I include reflections throughout. I have omitted specific details in the interest of participant anonymity and instead I have presented case studies with condition characteristics. Where I have included quotes from participants, if there were specific details included such as names or dates, I have excluded this and used brackets to provide a more vague description in order to provide context, without including any potentially identifiable information.

4.6 Case Study 1: Thomas and his nurse, Susan

4.6.1 Clinical characteristics:

- Permanent wheelchair user
- Age range: 55-65 years
- Tetraplegic
- High risk of respiratory tract infections
- Risk of malnutrition and sarcopenia
- Able to effectively communicate
- Number of staff involved in package of care: 4 (Susan is his main nurse)

4.6.2 Reflective narrative of my time with Thomas and Susan

I was fortunate enough to spend several hours with Thomas whilst this main nurse Susan was also present and providing daily care for most of our conversation. Thomas was very welcoming and explained he has taken part in a research project years ago and was happy to be involved. He started by telling me of the incident he suffered over 30 years ago when he was a teenager playing sport which left him with a life changing

condition. He talked of the rehabilitation process over an extended period where he was by peers with the same condition and how this provided some sense of normality and time to adjust to new sense of self.

He explained he was from an educated family of healthcare workers and prior to the incident which caused his condition, he was a "fitness freak" and the sporting influence in his life meant he was athletic but also had learnt discipline. He reflected on that time in his life and told me he "[he] could eat whatever [he] liked." He compared that to now and said "The thing is, if I weigh more, I then have to wheel it round" and went on to explain that he still eats a very varied diet. His knowledge and awareness of nutritional associations for his condition went further. He later explained "food has always been important to me but bowels as a spinal are difficult to manage and you need to do it through diet as much as possible as a spinal."

He explained that he "always used to eat meat but [his] ex-partner was vegetarian so [for some time] [he] was mostly veggie as my ex was a great cook" however during this time he "noticed [he] began to lose weight" and so he reintroduced some animal sources of protein.

Within his culture, he explained his mother and grandmother were very good cooks and he had always eaten well, food had always been a big part of his life. Now he was living back with his mother, his mother had taught the carers how to cook his meals.

In more recent years his mobility had begun to decline and seizures were becoming more and more frequent and so he explained he is "No longer as much as I would like to" (cook) "but I'm able to prepare some meals and instruct the carers how I would like it done, especially tuna." He explained that when he got new carers they rarely knew how to cook and would not be how he likes it.

The longer I spent with Thomas, he began to tell me more about his life, his personal life and career. He explained "At the point in time his injury occurred, there was no such thing as psychological help or support for sustaining such life changing injuries" and that the consultant had told him he would go to university and qualify as he had always planned to do. He reflected on growing up at that time and feels grateful because it gave him no time to consider life any other way, instead he was told by figures of authority in his life (his parents and his consultant) he would succeed and he did. He was humble when talking about this with me and explained he is also grateful for having his rugby team as that discipline and mentality is what has allowed

him to go on and lead a fulfilling life of career progression, qualifications, travel and different fundraising activities including skydiving. When I reflect on my time with Thomas, I cannot help but compare him, his life experiences, and attitudes to life to other people I have met in my personal and professional life. I found his attitude and achievements very inspiring.

The way in which he communicated his story with me was very matter of fact and that he accepted that, he explained his condition and his life in such an open way, with a sense of pride of his achievements and resilience that he had gone on to achieve so much. I found his mindset and honesty admirable and it sparked my interest in acceptance. My immediate and ongoing reflections of my time spent with Thomas led me to consider whether it is acceptance of a diagnosis and the new sense of self which impacts on how people engage with the prospects of their future.

Thomas explained that he lacks ability to contract his stomach muscles due to his condition and therefore has difficulty in expelling mucus from his lungs which makes him subsequently prone to chest infections which can require a hospital admission. He said this has not helped with his recent weight loss, together with worsening spasms of the legs which causes knocks and cuts to the feet, which sometimes progress into sores. At the time when I was with him, he had one low grade pressure sore. Spasms, and sores together with recent weight loss, and being prone to constipation makes me question why nutrition is not a more significant feature of his care plan. Within my clinical role, these would all be indicative that one may have increased nutrition and hydration needs.

Throughout my time with Thomas, his main nurse Susan was present and continually checking his vital signs and blood pressure and so I began to explore why this was necessary. Due to the condition of the client, he is high risk of a secondary condition which can cause blood vessel damage or cerebrovascular attack and fainting. If signs are not closely monitored, it could be fatal. A management and monitoring plan for this is outlined with detail within the care plan. Having come away and spent some time researching his secondary condition, I have here provided the explanation I was provided by Susan as well as some additional explanation to provide context. At the time, Susan explained it “is caused from the blood flow from head to the stomach after a meal is eaten. Its prominent in spinal patients as the valves which usually control the blood supply don’t work as they should do”, this causes large fluctuations in blood pressure and symptoms such

include uncontrolled hypo and hypertension, brachy cardia (under 60beats per minute) and tachycardia (over 100 beats per minute). In Thomas's experience, he suffers from dangerous fluctuations in blood pressure, particularly post prandially as the blood rushes to his gastrointestinal tract for digestion and absorption after eating. Whilst I was with him his blood pressure reading was 180/111- extremely high which can cause damage to blood vessels and in some cases cause cerebrovascular attack or death and hence management of this is a large feature in his care plan.

Thomas tries to "self-regulate by having high protein and vegetables, often no carb or fat because of its impact on blood pressure." This was poignant for me as a dietitian to hear that he is very aware however that he is not receiving any professional input to support him with this. The fact he is losing weight, experiencing increased muscle activity and becoming less responsive to medication for autonomic dysreflexia means this key factor of nutritional intake and quality has scope to improve his quality of life, if explored. He is very well informed about his condition and his needs. In term of food and fluid he is very responsible and makes informed decisions around eating well. He tells me being able to cook has been a key component of the ladies he has been in a relationship with which shows his love for good food which he considers stems from his upbringing. It leads me to question why within his care plan, nutrition is not a feature given his predisposition to constipation and weight loss. Why is constipation treated with medication or intervention and not by improving nutritional quality? Is it that this highlights the need for increased appreciation and awareness of nutrition by those devising care plans?

The strong bond between Thomas and Susan was prominent, seemingly almost like a family relation which is unsurprising considering Susan has been caring for him for 5 years. They discussed her family who she was leaving to go and visit. The closeness of their relationship and the fact Susan knew him so well and could identify any subtle changes in his condition was powerful and demonstrative that long term care with the same healthcare professionals and carers can be hugely beneficial for both the client and achieving very high-quality care. This also highlights the difference between long term home care and care in acute or community care in the NHS where visits are shorter and typically with different care professionals.

4.6.3 Key findings which relate to nutritional need

There is evidence of nutritional need which is not being met which has resulted in ongoing weight loss and is an indication of undernutrition.

Thomas' sporting background, socioeconomic status, education, family and culture have all attributed to his views and values of food and self-management of his condition.

Thomas' nutrition and food preparation have been managed by himself and his mother teaching his carers how to prepare food and cook for him which has been an increased requirement as his dexterity and ability to do this for himself is diminishing.

4.6.4 Key points for consideration

Thomas is able to advocate for himself by instructing carers what food he enjoys and how he likes it to be cooked. He and his mother have taught his carers how to cook as they were not currently able to do so.

4.7 Case Study 2: Katie and Steph

4.7.1 Clinical characteristics

- Permanent wheelchair user
- Age range: 25-35years
- Genetic condition typically causing compulsive overeating
- Risk of dual burden malnutrition and sarcopenic obesity
- Tracheostomy and ventilation
- Catheter
- Double up 24-hour care
- Limited verbal communication with Katie due to genetic condition and associated learning difficulties
- Home adaptations for wheelchair use, house conjoined with parents for supported independent living
- Funding from winning a clinical negligence case

- Number of staff involved in package of care: 10-13

4.7.2 Reflective narrative of my time with Katie and Steph

I met Katie and Steph (Katie's mum) at their home and spent several hours with them there. I was lucky enough to be shown around their house transformation which they are very proud of. Katie was bubbly and dressed up to be going out with her carers for an afternoon activity so I spent a long time chatting with Steph.

Katie's mother Steph explained she became "very involved with the [condition specific] society because when [she] she gave birth to [the client], general awareness of the condition was relatively poor and the consultant told [me] when [the client] was born that [she] would "always be a bit thick and a bit fat." She reflected on this comment, remembering how difficult that time in their lives was, for the whole family especially due to such little awareness of the condition and the unknown nature of the future.

Katie was born with a genetic condition which was managed without carers, instead the family researched the condition and Steph became her own expert in managing it at home. Steph described Katie's childhood presentation as "relatively high on the intellectual scale but lower down on physical development levels" and explained that "She didn't walk until she was 4."

Steph has a keen interest in nutrition and well-being, however she has no nutritional training. CareCo Healthcare have not provided any help on nutrition and health but it is something that has always been important to Steph, who was wearing activewear and explained she's heading to the gym with her husband after meeting me.

The family managed traits of compulsive eating by never banning particular food groups, instead allowed small quantities of higher calorie or fat foods. Katie responded well and through meal planning and organisation, she enjoys having her portion of food and does not ask for more. This has continued to work very successfully. Her meals are planned on a whiteboard which specifies what she can expect to eat and which of "the girls" or "her besties" (her carers) she will be eating with.

The family invested in pretty glasses and plates to enhance her mealtime experiences which are always a social event, when the carers will sit and eat with her.

Following an erroneous surgery from a complication associated to her genetic condition, Katie is subsequently a permanent wheelchair user with a tracheostomy and ventilation. Given this event, Katie and her family entered a court case for clinical negligence, as she would now require complex long-term care and for that care package to be funded. While the court case was going through, the family lived for 9-10 years sharing a living area with the carers meaning the family and family life was altered as they had no space of their own. Living with carers and having the family home medicalised had a significant impact on family life. Steph mother explained that having a child with additional needs who spent long periods in hospital took its toll and meant her son "spent a large chunk of his childhood being raised by his Nan." I felt empathy for Steph and the family when she was opening up about this as the magnitude of what the family have been through is evident and the wider context of living with a long term condition and caring for someone with a long term condition having a rippling effect on the family and their network.

After winning the clinical negligence case in 2006, the funds paid for a house transformation which bought the plot of land to extend the house and have a house which provided adequate space for the client with a co-joined house for Katie's parents which is linked by intercom but allows both parties to have independent living space.

The lead carer on the team and has now been working with the client for 11 years. Her relationship and knowledge of the client and specific management of her condition led to her involvement with designing the house transformation when the court case was won. The house is open plan, and Katie has a whole kitchen to herself which has lower work tops, units and appliances so that the client can be involved in meal preparing with "the girls." It has mood lighting so they can play music and it is conducive to a happy mealtime experience which the client looks forward to. The value that has been added from staff involvement with the process has been life-changing for Katie and their family and I felt inspired and slightly in awe of this case upon my leaving.

Steph has pushed for CareCo Healthcare to fund the lead carer's wage as a Team Lead and are now in contact with CareCo Healthcare to push for her to be promoted to senior carer, given her competency in managing the care plan and Katie's complex care needs. The fact that the family have initiated and advocated this is really interesting and sparked by curiosity as to why it is not coming from within CareCo Healthcare to promote their own staff, especially given the known fact of staff turnover and how at times, the workforce can be transient due to pay, work benefits and more, as discussed elsewhere.

Before they won the court case, carers used to bring in their own lunch and feed Katie separately. Katie's parents would eat the same as her but her carer would feed her and then go home and eat their dinner. Now the carers will cook and eat with the client which is why it has been so important for Steph to ensure they are trained in eating well and cooking. If the girls ate separately to the client or made an unhealthy choice when eating out, it would cause Katie to become distressed. Now, carers will get lunch and dinner provided, ingredients are funded by the Katie's parents as they value the benefits this has for managing Katie's condition and wellbeing. It is really interesting to consider what their lives could be like if they hadn't won or the funding what not as adequate to allow this. Steph's husband sold his business and both parents are educated and able to care for her and provide. What would happen to someone who had no one to advocate for them in this way?

Steph goes on to tell me "to live as independently as possible requires planning as [Katie] has a busy social life with clubs, activities and trips." Each year she has trips to Butlins, Centre Parks and Winter Wonderland. To go away for days at a time, requires 4 carers to be available. In total, Katie consistently has between 10 and 13 girls on her care team. For her to have annual trips which consist of several days away at a time is expensive and Katie's parents help to pay for the carers in order for Katie to sustain the lifestyle she has which brings her such joy.

Steph is still very much involved in overseeing her care and admits she runs the shifts "like a military operation" and [she] "has made checklists, stock check lists and cleaning rotas for [my] girls." With regard to nutrition, meals are planned in advance on a large whiteboard to help Katie to remain settled which is amazing to see but I wonder if Katie's care was left to the responsibility of the care provider only and did not have an advocate, this would never have been such a positive outcome and her quality of life would not be the same.

What if Steph did not have a keen interest in nutrition and wellbeing and did not oversee that Katie consumes a healthy balanced diet or monitors her weight? Every evening, Katie and Steph have an hour before bedtime which is their private time to debrief on the day and if there is anything Katie is concerned about, she will express it so any issues are discussed and can be resolved. What about those who have no one there for them?

Katie has a financial deputy who is responsible for managing finances and ensuring decisions and costs are in the best interest of the client. Outgoings that have been required include a "Powered wheelchair was £18,000 and the double care package costs £250,000 per year. We had to pay £6, 000 upfront for the van." The magnitude of money involved in care packages is something I have not experienced before within the public sector and I was astounded. Upon leaving their home and reflecting on my drive home I wonder again how individuals or families would afford their care needs if they hadn't won a negligence claim or they did not have the means to pay for things up front. Disparity in care and the impact that can have on the individual and wider context is a key issue I keep returning to when I consider this case.

Katie's family discussed that there needs to be a different level of training for CareCo Healthcare staff either prior to starting a package of care or on the job training with competencies to be signed off, including awareness of nutrition, meal preparation, fluid charts and bowel monitoring. Where do the care providers stand in terms of taking ownership for the quality of care provided rather than just basic levels of need and ticking checkboxes. Going over and above to really tailor peoples care and improve their self-management and quality of life? If Steph was not overseeing these aspects of care, I wonder who would as Katie isn't able to advocate for herself due to her genetic condition and lower cognitive level.

Steph explained that for existing competencies of staff, they have experienced in the past "Carers needing to be signed off for competencies but there are no nurses around" and the family have advocated for the client to ensure these needs are met. But again, this leads to question what is going on and how tightly staff training and safety of practice is being regulated by those responsible for checking in CareCo Healthcare. Her family have shaped her care and her mother openly told me that she has had many run ins with CareCo Healthcare with regard to fighting for a team leader role. Her family are also responsible for interviewing new recruits to the care team and oversee that they are trained for Katie's specific needs. Her mum has schedules and has trained the carers to cook nutritious meals and writes weekly meal plans to make mealtimes more manageable

which helps to manage Katie's genetic condition. When recruiting a new carer, they explained that "Care staff come for a trial shift" but "if they are overweight or don't get on with [Katie] they will not be employed" because nutrition and eating well means a lot to Katie and her family and so to have a carer who does not comply with this would be disruptive to her self-management and her routine.

4.7.3 Key findings which relate to nutritional need

Nutrition is managed due to Steph's interest and drive for healthy dietary choices.

Steph has implemented meal plans which Katie helps to decide on, to manage her genetic condition and make mealtimes enjoyable. The family fund the food shopping for Katie and her carers so that carers cook and eat with Katie as well as eat out.

Winning funding from the clinical negligence case has enabled open plan house renovations and modified kitchen worktops so that everything is accessible to Katie which improves independence and good environment for mealtimes.

The family are 'particular' about new staff and if someone is overweight or not willing to comply with eating healthily in front of Katie, they will not be accepted at the meet and greet. This would be detrimental to Katie's routine and cause her distress.

4.7.4 Key points for consideration

Katie leads a very fulfilling and active life with a busy social schedule with double up 24-hour care, funded by the clinical negligence case, following her erroneous surgery and also partly funded by her parents.

Steph advocates for Katie and oversees high-quality care. Steph has trained the care team to cook nutritious food and choose nourishing meals when they are eating out with Katie. If Steph was not there or did not have

a pre-existing interest in nutrition and health, would Katie's condition be managed differently, and would her nutritional intake be as regulated as it is now? This is of key interest given Katie's genetic condition.

4.8 Case study 3: James, Daniel, James' wife and CareCo Healthcare branch nurse

4.8.1 Clinical characteristics:

- Severe acquired brain injury from fall on the street intoxicated March 2015. Found unconscious with bruising to the back of head.
- Age range: 55-65 years
- Good communication, partially limited understanding and occasional behavioural challenges as a result of brain injury
- Spent one year in hospital for recovery and rehabilitation
- Had a ventriculoperitoneal shunt inserted
- Chronic loss of smell and taste following severe sinus infection prior to ABI
- Symptoms presented – Parkinson's symptoms developed with Motor retardation and frontal lobe dysfunction
- Developed Type 2 Diabetes since under care of CareCo Healthcare
- Risk of dual burden malnutrition
- Weekday care
- Number of staff in package of care: 1 (Daniel is his only carer)

4.8.2 Reflective narrative of my time with James, Daniel, James' wife and CareCo Healthcare branch nurse

During initial discussions with the senior team at CareCo Healthcare, I was warned prior to meeting with James that due to his brain injury, communication may be limited due to reduced concentration and reduced ability to maintain engagement. They explained that on previous occasions in annual reviews conducted by the branch nurse, his attention span has been small, meaning he will get distracted and wonder off into another room. This was really useful for me to know prior to my meeting him so that I could adapt my communication style to short simple sentences to try and maintain engagement, meanwhile appreciating that may not be possible.

The branch nurse introduced to me to James as a dietitian which I feared initially would present a barrier as I had been warned he may not want to engage with me in fear I would provide dietetic advice. And at first when I attempted to build rapport with him he responded "I like being advised but I don't like being told" and "I like what I like, I'm not going to eat a plate of lettuce just because someone tells me its good." I therefore spent time with him to reassure him I was not there to assess him nutritionally, and navigate my way around moving from being a dietitian to a researcher.

James lives with his wife in a block of council owned flats, his dad visits regularly and was also there during my visit along with his care worker Daniel who is funded to be with James for daytime hours on weekdays only.

James' food intake consists of a limited range of meals which he remembers enjoying prior to his incident and losing his smell and taste and he is not keen to try new foods and dislikes being told what to do. This continues outside the home if eating out, as the client will "state what he wants to eat, [he] will never read a menu." He told me that at lunch times "I go out and "buy something" which will invariably be "KFC, McDonalds, Pasta." Given James' condition, weight gain and diabetes I question, is it moral to take him to get a takeaway every day at lunchtime? Should it be a duty of care from the healthcare provider in terms of optimising health status, quality of life and longevity of life? Having taken time to reflect on James' current condition and way of life I notice his circumstances and choices highlight conflicting ethical principles in healthcare because through respecting autonomy, it is causing non-maleficence and neglects beneficence (Childress and Beauchamp 2001).

James goes to the pub three times a week with his dad and orders 1 pint of lager and lime. He used to drink just lager, but he said the "lime gives a different sensation in my mouth" he also "covers all his food in pepper" according to his wife and he supported this by admitting that pepper also provides some sort of sensation in his mouth. This sparked my fascination as I've not come across a client like this before in my clinical experience and so I was really keen to find out whether he had ever explored anything which gave him a different sensation as I felt there could be huge scope to explore and improve his mealtime experience. However, after reflecting on this with the branch nurse, she explained she was unaware of this until that day- which itself is an interesting finding and highlights that it was not assessed or addressed upon initiating the care plan. This then leaves scope for improvement because if there is potential for exploring cooking methods or use of herbs and spices to see if satisfaction can be enhanced.

Due to his condition, James is unable to prepare food alone, and requires supervision when using the oven and when chopping ingredients. Daniel does not get involved with cooking and exploration of different meals or healthier choices has never been explored. Evening meals are prepared with his wife who admits she does not enjoy cooking but on Sundays they will sit and eat a family meal at the table with their children who come to visit.

Due to James' condition, staff described "it is challenging to change behaviour and that is evidenced in the fact that previous carers have been asked to leave if they have told [the client] what he can and can't do." However, from a care provision perspective and considering duty of care, it is surprising that James is not being better supported nutritionally. Prior to his incident, he was pre-diabetic and now has diet-controlled type II diabetes. His wife was originally responsible for measuring his blood glucose readings (which is stipulated in his care plan). However, is no longer doing so which it appears to be a result of a combination of factors. The first being that James' wife suffers from low mood as the branch nurse explained his wife has depressive episodes and struggles to cope with anticipatory grief of James' former personality and their relationship. The second factor is that due to his condition, James can be impulsive and non-compliant with help or advice. The branch nurse told me after leaving his house that he "looks like he has gained weight" and "his face is looking "puffy" which "can be in indicator of high blood pressure, a proxy of high salt and saturated fat intake".

These points are significant when I compare these visible measures of overnutrition to Daniels's opinion that there are no concerns regarding James's nutritional intake. There are no nutrition, hydration or weight charts in his care plan or daily logs however Daniel did say "in the summer we make sure he's drinking enough" which is an objective measure based on interpretation. When I then consider this against what is stipulated in James' care plan: "To encourage a good nutritional intake from a wide variety of food groups" it is surprising firstly, how vague and subjective that statement is and second, that it is not being actioned. Does this open a question to the awareness or understanding of nutrition particularly in carers who are providing less complex care or social care? The significant question raised from meeting James is one that has arisen to an extent in both previous case studies: where is the line drawn between patient autonomy versus advocacy in terms of duty of care and making decisions and goals in the best interest of the patient? This concept is developed and explored in more detail in chapter 5.

Following his injury, risk of deterioration of James' neurological and cognitive abilities is significant. His wife explained that medical management is required and if he doesn't take dopamine, then "swallow is the first thing to go, then it will be his mobility" she went on to sadly say the nurses at CareCo Healthcare are "looking to change his medications as his body is becoming immune to dopamine, despite it being good for his mind and cognition, can cause slurred speech and dribbling." James cannot communicate how he feels or if he is experiencing symptoms of decline and so identification of this is reliant on his wife and Daniel. They went on to explain that they know when James is poorly, a main signal is when his lips turn pale.

Daniel is employed to work with James from Monday-Friday 7am-4pm, which is funded by the local Clinical Commissioning Group (CCG). When I left James' house and spent the afternoon with the branch nurse, she explained that "last year the CCG wanted to reduce funding but his wife is not coping" and at her last visit "she presented as very depressed and low mood, grieving for the loss of her husband as he was." Having come away and reflected on this I have explored this phenomenon in greater depth and understand it to be a concept otherwise known as anticipatory grief which can be experienced by the individual or the wider community of the person diagnosed or suffering.

Having come away from James' flat, I discussed his case with the branch nurse in detail and the new knowledge that he has no enjoyment or sensation from food. We discussed the risks of his weight gain

meanwhile CareCo Healthcare don't appear to be actively engaging in promoting healthy eating. The branch nurse said "There is a fear of being too pushy and losing the client (and their families) trust and putting that relationship between the care provider and the client in jeopardy"

A key discussion point with the branch nurse about James was around the challenges of organising and providing someone like James. We discussed James' condition which resulted from a serious fall to the street and has now left him with a life-long condition, which has framed his new way of life and interactions everyone around him but especially with his wife and family. Communication is limited to short sentences due to brain injury, so James is only able to understand and converse very superficial and low level detail. We discussed how interactions can be challenging for both the carer and care provider when trying to address change "as if anyone tells him he cannot eat or drink something, he would not want them any longer which then requires additional work to recruit and train someone else." In which case, finding a carer with the right personality set to enable him and communicate well with him and his family is a challenge.

We went on to discuss challenges of recruiting carers and the workforce of carers who provide companionship, social care or non-complex healthcare. The branch nurse is involved in the recruitment process and developing care plans and highlighted several challenges she has experienced. Level of English (spoken and written) and level of education or understanding were two key factors which the branch nurse raised with reference to the need to communicate with client and the care provider verbally. The ability to communicate adequately in written English is fundamental to record keeping ensuring safe care and that it makes sense, is concise and is legible. She explained that record keeping was one area where CareCo Healthcare has supported Daniel in the past. She also went on to state "if communication, or level of written English written is low, it is unlikely a non-complex level carer will ever progress to complex care for safety reasons."

It was interesting to hear the challenges the care provider faces in terms of the workforce they are employing, training, and attempting to retain. The branch nurse also discussed the "high level of staff turnover" which means continuous attempts made to keep staff on their database. However, we also discussed that lack of variety within the care team for example with James, as Daniel is his only carer, could pose a barrier to good care. The branch nurse identified "if [you are] seeing someone daily over a number of years, it is easy to

become complacent due to increased rapport, seeing him everyday and get used to certain things." This opinion I agreed with to an extent, although the benefits of Daniel spending so much time with James was that he was able to recognise when James is declining, and he cannot verbalise that himself. Although it does raise a question if there is a new carer or a second carer involved, would it help to bring about goal setting. The branch nurse agreed with this and questioned the potential of this for someone like James "As a new or different carer, what are you bringing to the client as a carer? What goals are you working toward?"

In terms of James' nutrition, the branch nurse informed me that he is unfortunately "Very high risk of losing his ability to swallow" and "eventually may have to be PEG" (percutaneous endoscope gastrostomy tube- a long term method of enteral feeding through insertion of a tube into the stomach)(NHS 2018). The fear is "if he would consent and in the future by the time he may need a PEG there is question as to whether by that point he would be able to provide consent." We therefore discussed the potential to improve his current care plan which could involve, identifying nutritional need through observing a meal time, goal setting to try more nutritious food and takeaway options available in the local area. Goal setting with flavours and textures to explore smell or taste sensation which could improve satisfaction and the potential of CareCo Healthcare to provide training on cooking or a healthy diet.

4.8.3 Key findings which relate to nutritional needs

There are nutritional concerns which are not being addressed as overnutrition was visibly evident to the branch nurse who commented on his weight gain and "puffy face."

It appears nutritional assessment was not conducted at the commencement of James' care package. Therefore, his lack of smell and taste was not known until I met him. There is now an opportunity for goal setting to be explored in order to enable James to enjoy his lunchtime walk but he could explore what is in the local area which is a healthier option. Goal setting could also aim to explore different taste and texture other than lime and pepper which may provoke a different sensation in James' mouth and improve satisfaction from food.

James was pre-diabetic before his incident and now has a confirmed diagnosis of diabetes which, as per his care plan is supposed to be monitored by regular blood glucose readings however this is not happening.

James walks to get a takeaway everyday with his carer, Daniel which are meals high in fat, saturated fat and salt.

4.8.4 Key points for consideration

Reaffirming my role to myself and to research participants as a dietitian and researcher was key and negotiating this role enabled me to successfully communicate with James, despite initial caution.

Here lie conflicts of healthcare ethics when we consider autonomy versus non-maleficence and beneficence. James' choice is to buy a takeaway for lunch every day and is assisted by CareCo Healthcare to action this choice. However, given the long term associated risk with this consistent behaviour, there is conflict with beneficence and non-maleficence.

There is a battle between CareCo and James. CareCo described James as a stubborn man who is not willing to change and so the Daniel takes him every day to get a takeaway despite high blood pressure and type II diabetes. CareCo expressed there is fear of being too pushy with a client and losing their trust or that contract altogether however his diabetes his now not being monitored and that may pose risk in the future to diabetic complications.

4.9 Case Study 4: Sandra and Rhonda

4.9.1 Clinical characteristics:

- Permanent wheelchair user
- Age range: 45—55 years
- Acquired brain injury following sub-arachnoid haemorrhage

- Good communication, partially limited understanding and occasional behavioural challenges as a result of brain injury
- Behavioural challenges (sexually inappropriate, cognitive changes, impulsive, can lash out, scratch, bite or hit carers)
- Risk of dual burden malnutrition and sarcopenic obesity
- Lives in family home with children and grandchildren
- Home adaptations with lift and hoists in every room for transferring
- Funding from winning a clinical negligence case
- Everyday 24-hour package of care
- Number of staff involved in care: 7 (Rhonda is the Team Lead of Sandra's care)

4.9.2 Reflective narrative of my time with Sandra and Rhonda

Sandra is a middle aged sociable and outgoing lady who was previously known as Miss Active as she was a fitness instructor (a pseudonym has been used to maintain anonymity). Sandra lives at her home with her son, daughter in law and grandchildren. Sandra's CareCo Health team leader Rhonda was present throughout my time at Sandra's home. Rhonda previously trained as nurse but changed careers for personal reasons. She cares for Sandra 3 days per week and oversees all carers employed in Sandra's care package are trained and competent to provide the care required and aware of any changes to her care plan. Sandra's care package is 24 hours a day, 7 days a week now but in the past her family who reside with her had provided night-time care. Rhonda explained that it "didn't work out" and it was decided that the care package needed to be increased to full time although while we were sat in the family home, Rhonda appeared uncomfortable and said that she was not able to discuss it further.

Sandra is a permanent wheelchair user following a large cerebrovascular attack over 10 years ago. Between Sandra and Rhonda, they explain "The doctors at the time gave her 2 hours to live" and "she was put into a coma for 9-10 months. Instead of being treated at the time for a cerebrovascular attack, [Sandra] was treated

for meningitis." It is due to the funding from winning the clinical negligence case that Sandra was able to afford home modifications. Whilst the case was ongoing, Sandra has been placed in a nursing home for 5 years. She had previously been had a tracheostomy and percutaneous endoscope gastrostomy tube inserted for breathing and nutritional intake purposes, respectively.

Sandra's care package supports her to maintain her social personality by going to activity and music clubs weekly which allows her to interact with other people with disabilities. Through her funding, Sandra was able to purchase a van appropriate for wheelchair users however only two of the seven carers in the team can drive. Reflecting on this, my mind drifted back to Katie's case, whereby her funding too had helped her to live the life she wished through being able to afford adapted technology. This aspect also led me to consider challenges of recruitment and skills of carers which can either help or hinder the level of care provided. By this I mean, given the transient nature of the care workforce, if one or both of the carers who can drive left and CareCo Healthcare could not recruit another suitable carer who could drive, what would become of Sandra's quality of life?

Due to her condition, Sandra's behaviour can be challenging, and she is known to shout, bite, punch and scratch. She also touches people in a sexual way and uses sexual language toward people which is known within the care team to manage but has caused some problems within the community in the past. During my time with Sandra, she shouted at Rhonda several times and attempted to hit out which Rhonda dealt with by staying calm and asking her to stop doing that. The episode I observed was brief, and Sandra returned to talking to me and laughing as she had been prior to this. However, it made me aware of Sandra's erratic moods because of her condition which can be challenging for the care team to manage, particularly if she is exerting physically aggressive behaviour.

Something which Sandra is not happy about with her care at the time of my meeting her was that Rhonda is trying to encourage the carers to give Sandra smaller portions of better-balanced meals. Due to Sandra's considerable weight gain and the fact she is not expending much energy, Rhonda currently does the food shopping and is trying to encourage healthier choices at mealtimes. She explained that cooking more healthily and aiming for balanced meals was from her knowledge, she had "no training on nutrition or preparing a good balanced diet or drinking enough fluid" from CareCo Healthcare. She felt that "support with nutrition and

cooking to train carers without the skills so that [we are all] on the same page would be better" as three members of the care team cannot cook. This then adds pressure to the responsibilities of those who can, rather than cooking being shared equally among the care team. Rhonda added that when trying to provide a consistent message and care, "portion size is not the same within other people and with the changeover of staff and no training and they have not yet got used to [Sandra]." Rhonda continued to explain that the "family do not get involved with meal preparation but will buy whatever [Sandra] asks for from outside the home" which is counterproductive to achieving weight loss. Sandra told me with a big grin that "Chinese takeaways are my favourite."

Here lies a number of challenges for the patient and the care team in that Sandra expressed she doesn't like her weight gain as she "used to be a size 8" but that when the care team try to promote healthier choices, she rebels. The issues raised here include the challenges of care staff turnover, lack of training and awareness, Sandra's impulsive behaviour, heightened by the fact that the family are opposed to complying with the aims of the care team.

Rhonda explained that Sandra has been trying to take food to bed which is "forbidden" as the care team are trying to monitor her food intake. Sandra has not liked having her food restricted and told me she has been hiding food and sweets between creases of her skin, in her belly button and intimate area in attempt to sneak snacks to bed. This has been noticed by the care team as it could be potentially dangerous.

It occurred to me here that compared to James' case, Sandra is being actively restricted which is causing further repercussions. Advocacy is outbalancing autonomy with the view that carers should be aiding weight loss. in contrast James' autonomy is superseding advocacy which is putting him at long term risk too. I will draw on these findings in greater depth later in this chapter.

While I am at Sandra's house with herself and Rhonda, "Nanny" arrived who is Sandra's mother. Observing the interaction between Sandra, Rhonda and Nanny is interesting as Nanny bought cream to help Sandra's skin but it has come from overseas and not a prescribed treatment. Rhonda tried to explain that she will ask the other carers to apply the cream, but they may not do it as it is not a prescribed treatment. Nanny's response

was quite aggressive saying “this is my child” and “as soon as someone else thinks that she is their child they have to go.”

Observing this interaction is interesting for me as this is one of the first insight which uncovers the battle between the family best interest and carer best interest. The care staff who are following their protocols and care plan to be in line with what the care provider expect to work within safe practice. However, in this case, the family believe they know what’s right and will not be told otherwise by the care provider if there is a conflict of interest. Rhonda explained that Sandra previously “used to have an occupational therapist, physiotherapist and dietitian in the community which were part of the care package but that stopped” and when I asked Rhonda why, Nanny was there and she said discreetly that she is not allowed to discuss it. I later enquired with the branch nurse and branch lead what had happened. They explained that the healthcare professionals advised the holiday they had planned for Sandra was not safe, and if the family decided to go ahead, they would no longer work with them. This makes me wonder whether there should have been a safeguarding report made. This situation highlights another moral conflict between who decides on best interest.

4.9.3 Key findings which relate to nutritional need

There is evidence of overnutrition as Sandra explained she has gained a lot of weight over recent years.

Food is being withheld, considered to be in best interest to help her achieve weight loss however this is causing Sandra to hide food in intimate areas and skinfolds which could be harmful.

Rhonda is trying to advocate for change and prioritise nutrition, but the care team are not trained and there is difficulty providing a consistent message among the team with lack of training and recruiting new members to the care team.

4.9.4 Key points for consideration

Patient autonomy versus advocacy here is a key issue especially given that Sandra is not physically able to act upon her wishes. CareCo Healthcare are aware of her weight gain and carers are actively trying to manage her nutritional intake and modify her portion sizes, advocating for her and acting in best interest. However, this is creating potentially harmful behaviour.

Challenges of staff turnover and lack of training and awareness of nutrition were raised as key issues with trying to provide consistent care. This was augmented by family versus carer conflicts of best interest was very insightful to challenges of providing care and doing so consistently. How does the care provider effectively and safely navigate their way around these complex and deep routed dynamics in a client with complex cognitive challenges?

As with Katie, Sandra won a clinical negligence case which has paid for her home modifications with hoists in each room and a lift from downstairs to upstairs enabling her to remain in her home environment with her family. The funding too, has paid for her van which allows her to have a good social life and maintain interactions with others outside the home which is gives her enjoyment and satisfaction in life.

Family dynamic of who decides best interest of the care plan when providing care at home as family interactions can have a huge role and ramification for care provision.

4.10 Case Study 5: Samira and Karen

4.10.1 Clinical characteristics:

- Subarachnoid Haemorrhage and left sided weakness
- Age range: 65-75 years
- Able to communicate well, limited on rare occasion due to language barrier
- High blood pressure
- Mild condition affecting joints
- Depression
- Risk of dual burden malnutrition
- Lives in assisted living accommodation

- Social care
- Number of staff on care package: 1 (Karen is her only carer)

4.10.2 Reflective narrative of my time with Samira and Karen

I met Samira in her open plan first floor apartment within her assisted living residence, her care worker Karen was present throughout our conversations. Samira has lived in her assisted living apartment for several years and it is local to her children and grandchildren who visit her weekly to take her for dinner or days out.

Karen has been Samira's carer for 4 years and is funded to spend several hours with her 5 days per week. Both ladies were similar in age but ethnically and culturally different, yet they appeared to be close which is reflected in Karen's statement "When we go out, we are shopping buddies, I don't ever say that I am her carer because its true we are just like friends." Samira explained "I enjoy going out (with Karen)" and "sometimes [I] get sad when [I] stay at home and especially when [I am] on [my] own." This was highlighted later in the day by Karen: "When Samira stays indoors, she feels down, don't you (to Samira) so most of the time we go out and go to town and do some shopping." Samira explained that despite living in an extra care assisted living accommodation, she dislikes spending time in the main hall (with other residents) "because [I don't] like to socialise with them, they are not like [me] and rarely leave the home." Samira and Karen comment that they "They will watch her come and go and comment that she is always out" as Samira keeps busy with exercise classes and visiting her cultural day centre. Upon reflection, this would not be possible without CareCo Healthcare or a care package for her as she would not want to go out on her own. Her package of care being provided is allowing her to maintain her quality of life.

Samira and Karen's relationship was lovely to observe, their kindness and fondness toward each other was very much like a friendship and Karen openly admitting when they go out, they will say to others they are friends. She mentioned this was positive in the sense it reduced the potential stigma from the external community about being a carer or the person needing a carer which is interesting that she feels this way on Samira's behalf. Their relationship as friends also removes power balances between being an employee and the person they are employed to care for.

Paradoxically, the perspective of being stigmatised in the community for being carer or being someone cared for which leads to the pair telling people they're friends is an interesting concept and one I have not before thought about in much length or very much detail. However, when exploring the interactions between staff and clients or service users I guess it does become meaningful. Would I be a help or a hindrance to refer as a friend?

Before the day I met Samira, one of the branch nurses had told me she was excited to meet me because I was a dietitian and she was keen to get some weight loss advice. When I entered her home, I was aware she has assumed my identity as a dietitian and therefore this was her focus and so as with James, I spent time explaining that I was here to do some research and find out more about her and her experiences. On reflection of this, Samira was eager to meet me as she knew I was a dietitian and she was hoping for an assessment and some sort of advice to help her with a weight loss goal. I found it quite tricky at times to remain in my researcher role and not slip into my dietetic role where I would usually do an assessment with a patient. This for me was something I kept having to remind myself throughout my time there as I was there as a researcher and not as a dietitian. That said, I later felt morally conflicted in my mind because I was there and had the skills and ability to help her and I did make some suggestions because she was eager to improve her BMI rather than me go in and ask questions and leave her with the same dilemma. I found it a battle that I could help and wanted to help rather than meet her and get what I needed and leave. This whole concept I found made me question myself as well as why CareCo Healthcare were not promoting healthier eating and goal setting to improve her overall health.

Within her care package, Samira has set herself her own goal in terms of weight loss which is not being addressed or supported by CareCo Healthcare or raised by Karen. My identity was revealed as a dietitian prior to our meeting and she perceived I could help which made me morally conflicted with providing advice versus research and the interference that causes with the naturalism of conducting ethnographic research.

Samira explained "when I went to the hospital, someone told me my BMI was too high, but I never had help after that." She was discharged home and wanted to lose weight but did not receive support or education in how to go about doing so, admitting ""I struggle with my weight, but I always have a good appetite". Samira is physically able and confident in the kitchen, requiring only a little assistance with chopping ingredients. She

cooks cultural main meals for herself and will eat the leftover portion for lunch the next day. Samira predominantly will only eat food prepared by herself as she is a member of [a spiritual community] who share the belief that a positive mind and positive thoughts are transferred into the food. When concentrating the mind with good energy and vibration from [a higher spiritual deity] brings positivity and wellbeing for those who eat the food. Samira has chronically suffered with bowel problems and reduced bowel motion, which she tries to self-manage through ensuring she consumes fruit in the morning time along with nuts and seeds rather than use medication.

I noticed around her apartment there were lots of post-it notes with handwritten reminders and Samira explained she sometimes forgets things. Karen said "there were some issues with not taking medication as you (Samira) would forget sometimes wouldn't you" as in the evening Samira is on her own in the apartment. To manage this better, Samira bought an Alexa- a virtual assistant artificial intelligence technology and which she and Karen have set up to talk to her every evening and remind her to take her medication before bed. They told me "since we got the Alexa and set it up to remind her in the evening it's been a lot better."

This use of technology for medicine management or just to improve care consistency and help Samira live and manage her condition as independently as possible I thought was incredible. I'd not seen this before in clinical practice and it sparked my interest into the potential a technology like this could have in a range of people, with varying severity of their condition and varying daily needs to live as independently as possible. The benefit of this sort of intervention could not only improve the quality of life of a patient, reduce risk deterioration and hospital admissions. But further, if we consider the wider context of healthcare, especially its current constraints, it could be hugely beneficial in terms of cost, staff, and resource saving. For nutrition and hydration, the scope of this could be far reaching in that as dietitians, we could record meal plans or recipes we are hoping to implement into patient care plans which then could be installed to the technology and remind people to eat or drink regularly. Or in Samira's case, we could set prompts for health behaviours and reminders or prompts could be set at times tailored to the patient's routine.

Samira attributed meaning to having a friend and companion in Karen rather than viewing it as care. It makes me question how far along do lines become blurred between social support and befriending, if at all? And if so, is this beneficial or troublesome? Upon reflecting on the day I spent with Samira and Karen I think back to

my earlier conversation with the branch nurse at the beginning of my time in the field where we discussed in length the potential challenges which can occur when an CareCo Healthcare employee has worked with a particular client for an extended period of time, especially if they are the only staff member assigned to that care package. Through that discussion, the branch nurse identified risks of complacency in the workplace as both the carer and client get used to each other being around and begin to tolerate more, potentially notice slightly less than they may do if there was a job share or fresh pair of eyes going in and finding out right, what are the goals of this work and how can the care provider help you to achieve these? For example, with Samira wanting to lose weight and for her BMI to be in the obese category for her height, bearing in mind she has suffered from a cerebrovascular attack from a ruptured aneurysm, I do believe that there are dietary modifications which could occur to enable Samira to live a healthier lifestyle and optimise her BMI. And yet, although raising this herself as a concern, CareCo Healthcare and Karen have not. Where and whom does the responsibility lie to educate and empower Samira to fulfil these goals?

4.10.3 Key findings which relate to the nutritional need

Samira is physically able to buy and prepare her own meals, she is supported by Karen with her food shopping and food preparation by helping to chop vegetables.

There is evidence of overnutrition as Samira has been informed, she is obese however there does not appear to be a management plan to support weight loss, despite this being a goal of hers. Samira is of Asian ethnicity and overweight, which predisposes her to risk of developing type 2 diabetes.

If nutritional assessment had been done at the commencement of her care plan, a care plan could have been developed with her priorities in mind. Goal setting for weight optimisation could be implemented to help improve quality of life.

4.10.4 Key points for consideration

Reaffirming my role to myself and research participants to navigate away from my identity as a clinician and instead present myself as researcher. I felt morally conflicted doing so with Samira as she was eager to have nutritional help however I was only visiting in a research capacity and felt this may alter our engagement and hinder the line of enquiry which would be non-conducive for research purposes.

There is no one advocating for Samira to help her achieve her weight loss goal.

Samira is supported with social care and companionship in Karen and she can have a busy social life with exercise classes, shopping and visits to her day centre which bring her joy. Without Karen, or this sort of support, it is unlikely she would lead the life she does and that is humbling to witness how care provision can make such a difference.

Samira has used Alexa (Artificial Intelligence technology) to remind her to take her medication as that was identified as an area for improvement in her self-care when she is alone. It is inspiring to consider the wider context of its uses in the field of nutrition.

4.11 Case Study 6- Doreen, Greta and CareCo Healthcare branch nurse

4.11.1 Clinical characteristics:

- Progressive neurological condition affecting cognition, mood and movement
- Age range: 75-85 years
- Cardiac problems
- Effective communication
- Depression and anxiety
- Risk of malnutrition secondary to chronic low intake
- Self-funded 24-hour live in care

- Self-funds a Private chef
- Number of staff on care package: 6 (Greta is a main carer)

4.11.2 Reflective narrative of my time with Doreen, Greta and CareCo Healthcare branch nurse

Doreen lives at home in a very affluent area. Her carer welcomed the branch nurse and I inside and we drank tea from china cups and saucers. Doreen is cared for downstairs and in her large living room has a hospital bed, bedside where the carers also sleep. Doreen began to tell me of her late husband and describe the lifestyle they had once shared together, as she spoke, she did not appear emotive, instead in some way detached from her past.

She spoke fondly of her carers who live with her, referring to them as 'the girls' and explained 'I have the girls live with me so I constantly have people here, they make me cups of tea and prepare my meals for me.' Her care only started after losing her husband and she went on to say 'friends come to visit but rarely' and the branch nurse later went on to explain that these are socialite associates from her marriage and they seldom visit since her husbands' passing, and so she pays for live in care for company.

Doreen will 'ask the girls to get my shopping usually Waitrose or Marks and Spencer's, sometimes I write the list and they will get it for me' and then her chef cooks all meals. The branch nurse explained after our leaving that there are concerns regarding the chef who has been working for Doreen for a lot of years, prior to CareCo Healthcare care commencing. She explained that there is concern about the salary Doreen pays the chef for very little cooking and whether she is being exploited to an extent but that there is a loyalty expressed from Doreen and she is not willing to let her down. Having a long-term chef, Doreen explained 'I have always eaten well' and her intake will range greatly. She will have three courses at her main mealtime, the starter of which is 'bowls of homemade soup' and goes on to have 'omelette, chicken or fish with vegetables and potatoes.' She will also enjoy her pudding of 'sponge, stewed apples or crème caramel.'

Her chef was not present when I went to meet Doreen, but her carer Greta was present throughout. When we were speaking about nutrition, Greta highlighted 'I have not received any training specifically focussed on food or nutrition, but it would be interesting' but then added 'but because [Doreen] her chef we don't need to cook.' I found this really interesting because it highlights that there would have been a need for nutritional training had Doreen not had a private chef, which triggers my thinking back to the case of Thomas, Katie, James and Sandra who all have funded care and nutritional need, but carers who had no training or education regarding cooking from CareCo Healthcare.

Doreen was very welcoming and chatty, and it appears she enjoys the company of having people around. She spent the time I was there sat comfortably in her armchair; it was raining outside and when I said I was going to go home, she offered me to stay (which I politely declined). But it struck me she is quite fortunate to be able to afford the care she wanted to have continuous company; some others are not as fortunate. Doreen's case contrasts significantly to the other participants I met she was very endearing and I'm glad she is able to provide herself with the care she needs. The dynamics with her private chef, not wanting to fire her and the concerns raised by CareCo Healthcare are interesting, in that CareCo Healthcare have tried to highlight it but are not able to enforce any changes against Doreen's will.

4.11.3 Key findings which relate to nutritional need

Doreen's carers purchase her food orders on her behalf and an in-house chef who prepares her meals. Her carers have had no nutritional training, but they state it would be interesting.

4.11.4 Doreen's Key points for consideration

Doreen funds her own care needs which is predominantly companionship which prevents her being socially isolated and alone.

4.12 Dealing with conflicts of interest as a novice researcher: discussion with the branch lead and two branch nurses

After spending time with clients, care staff and relatives I returned to the branch office weeks later and met with two branch nurses and the branch manager as they had asked for feedback on my findings. Prior to the meeting, I had felt apprehensive as I was a novice researcher, with a broader range of findings and insights than I had ever expected, and I was unsure how I was going to navigate their expectations. I sat in a meeting room with the three women, all older, more senior and with years more experience than I had working within healthcare.

Due to the time I had spent with two of the women I felt it was a safe enough environment to speak openly (to an extent) and utilise examples of participants to question their current practice. I anticipated they may have had expectations upon my returning from the field. To navigate myself around this, I initiated the meeting with a confession that I had returned to debrief with a lot more questions about the service than what I had started my research with initially.

It was an unfamiliar position to be in where I had accrued to an extent, some insider knowledge of how care plans operate in a day to day scenario, as well as outsider knowledge of the process of public care services and dietetic expertise. This experience was something which the senior team seldom had the time or opportunity to do. To my knowledge, I am the first PhD researcher CareCo Healthcare has employed and so I can appreciate their interest in my experience and findings.

At this meeting, I presented the moral dilemmas I had come across through meeting a range of participants and posed some of the questions I felt needed answering. One of which remains with me the most as I presented James' case. I explained his weight increase had been identified by the branch nurse who accompanied me (and was also in this meeting) and highlighted his new diagnosis of type 2 diabetes. I then explained that upon getting to know James and his routine, I learned he is assisted to buy fast food (high fat,

sugar and salt) for lunch every weekday by Daniel. I posed the question "is it moral to be supporting him with this decision on a daily basis, knowing the risk and impact that this could inevitably cause in terms of cardiovascular health?"

This was met by one of the branch nurses who endorsed that she wouldn't like to be told what to do in her home and if "I fancied eating a pack of biscuits when I get home then I will." This led me to consider further how nutrition as a concept is perceived in everyone and the emotional and social attachment we have as humans which informs our choices. However, it also struck me as alarming that a registered nurse would be supportive of such potentially harmful behaviour. I then questioned "Okay, so if one of your clients had a respiratory condition, would you allow one of your care staff to assist him to the shops daily to buy a packet of cigarettes?" This was met with all three women enthusiastically saying no, that would not be allowed to happen. The presentation of both questions was met with very different body language reactions and verbal answers. I consider both to be essential to duty of care and beneficence when considering healthcare ethics and I go on to explore healthcare ethics in Chapter 5.

What was interesting is that the branch lead was unaware this was happening in James' case and commented "that's quite bad, I didn't know that was going on." This identifies the value of this method of research through gaining insight. What was also interesting is the branch nurse who had accompanied me to his flat when I met him, had until that day been unaware that he had no sense of taste, smell or satisfaction which led him to add lime or an abundance of pepper to his food. We discussed the missed opportunities within this case to prompt better choices, attempts for goal setting and exploration of different food or fluid which may enable James to have some satisfaction of his meals.

A second key topic of discussion at this meeting was low priority of nutrition within care. I explained that I had learned there was no current training available on nutrition or what constitutes to a healthy diet. I also highlighted that low cooking ability in carers had been noted in several cases, despite clients having unmet nutritional needs. We discussed challenges that include recruitment, disparities in level of education, understanding of English, cultural challenges, and nutritional awareness. The branch lead explained in some cases "you wouldn't be able to start asking them to cook salmon" "some wouldn't know what salmon is or how to start with cooking it." I do understand that as an organization and employer there are several barriers,

they are contending with but for me, this attitude toward nutrition and cooking as part of a care plan was surprising. I felt at the time, it appeared there was little motivation to address these challenges which is therefore unlikely to propel change or improvement. I still find this difficult to understand however I return to this point in Chapter 6 where I provide recommendations for driving future practice and addressing nutrition within care planning.

Due to this, I went on to present an excellent example of good nutritional care which I had observed in Katie's case, where Steph oversaw her carers and care provision daily. We discussed how her carers or as Katie affectionately calls them "girls" or "besties" now cook and eat healthily with Katie and the meal planning rota Steph and Katie formulate weekly to improve mealtime experience and self-management of her condition. Steph has an interest in nutrition and health and funds the weekly shopping for Katie and her carers to ensure meals and snacks are nutritious, well-balanced portions are regulated.

One of the branch nurses asked me what I think they should do and if I think that CareCo Healthcare are going to start offering cooking lessons to their carers because if so, that is not possible. I considered this and replied that if a patient is unable to access food or cook for themselves then of course, this needs to be considered at initial assessment and the care plan should account for that need. I asked whether if a patient were unable to administer their own medication, would CareCo Healthcare employ a carer who also would be unable to administer this for them? This appeared to trigger a change in perspective, and we discussed the importance of addressing all needs of a client. Barriers to providing education and training for care staff discussed in terms of lack of facilities and how the additional cost, resource and time constraints that may bring about.

4.13 What can we draw from this data?

Here I will conclude key findings from my research and draw on similarities across cases as well as distinct features. These findings are later explored in line with other evidence and theory in my discussion in Chapter 5.

4.13.1 Similarities across the sample of cases

A key similarity across all cases is that nutrition does not appear to be managed in a consistent or justified way which may be due to lack of nutritional awareness of training of CareCo Healthcare carers. Nutritional need does not appear to be identified or assessed upon initial assessment, nor at annual reviews which may offer rationale for why malnutrition is apparent in 5 out of the 6 cases in the context of both undernutrition and overnutrition. Each care plan stipulates "eating and drinking" but tailored nutritional input is not a current practice within this setting.

Across all case studies, the risk of (dual burden) malnutrition and sarcopenia or sarcopenic obesity is present. My clinical knowledge and experience as a dietitian allow me to identify clinical risk without formal assessment as I understand risk factors for these health concerns. This finding highlights the need for nutritional screening and care planning which is not current practice within CareCo Healthcare. I address this finding in Chapter 6.

Despite each case being very different, there was conflict between patient autonomy versus advocacy and the complexity of ethics in healthcare present in several cases and long-standing carer-client relationship can be beneficial and problematic for providing quality care.

Reaffirming my identity throughout the research journey to myself and participants was a common feature throughout my time in the field.

4.13.2 Distinct features

Duty of care versus client autonomy is not the same across cases when we compare James to Sandra. Both clients have expressed their wishes, both clients have significantly gained weight. Although the causes and context of weight gain is complex, James is being supported to buy takeaway food meanwhile Sandra is

having takeaway food refused by carers and portion sizes restricted. Which is right? There does not appear to be consistency or justification of care decisions and goal setting. Should people be supported to live independently and comply with patient autonomy or where is line drawn where duty of care should supersede this trajectory?

Another distinct finding is in the case of Katie and Steph. They devise meal plans to organise her weekly schedule and manage her nutritional intake. The family have worked hard to train carers so that Katie now enjoys mealtimes with “her besties” and carers are now trained to prepare and cook nutritious meals.

Samira is the only participant who mentioned that she is using smart technology to help manage her condition through reminders to take her medication every evening when she is alone. This has helped her to be more independent and self-manage her condition at times when she is alone.

4.14 Reflection of author from time in field

I set out upon my ethnographic journey to understand why malnutrition exists in people with long term conditions who have long term home care packages. I sought to understand the lives of people, to highlight barriers to nutritional wellbeing as well as facilitators. I wanted to understand what happens on a daily basis and how that feels for someone with a long-term condition as well as the carer, their family and the care provider. Yet, what I learned, was so much more.

My findings show that for my recruited client participants, overnutrition was a more common issue. I was not expecting to find this, rather my expectation was to find undernutrition but that was only evident in one case. I was surprised to find that nutrition need is not assessed or managed in people who have such regular contact with healthcare professionals, especially if they have diet or weight related goals, as with Samira. It was inspiring to meet such a diverse range of clients with unique and fascinating experiences and perspectives. Speaking to clients, cares and staff from the care provider enabled me to better understand the culture in this setting and how nutrition is not currently a priority but that there is scope for significant improvement.

I came away from my time with these people having learned from each and every story. My reflections have been ongoing from the first contact I had with CareCo Healthcare and different questions and scenarios still occur to me in the middle of the night. I learned from the care provider about logistics and operations in terms of recruitment, employee retention and turn over and the challenges from a wider perspective of running a business. I learned what work life was like for carers, nurses and managers who are responsible for caring for chronically ill people on a daily basis and the ups and downs which come with that. I learned of the relationships between carers, clients and families and the depth of value that comes from a long-term care package and having consistent care. And I learned from clients, real people with real conditions and how their lives have changed and evolved to manage their conditions as much as they are physically and emotionally able to do so.

I learned a lot about myself and my values and practice as a healthcare professional. I was able to question practice which was peculiar to me and what I know in terms of making every contact count and signposting. I was able to speak to branch managers and discuss practice, having identified areas for potential and scope to improve care, as well as continue to learn and reflect on the differences between private and public care.

Reflecting on my role and my values both personally and professionally I felt morally conflicted. The service user participants whom I had engaged with and were enthusiastic for dietetic input which I could not provide them at time, I felt I had let them down. I had explained that I would not be providing dietetic input as I was there in a research capacity and interested to find out about their experiences, however the more I consider this I feel guilty that I could have helped. I had the knowledge and capacity to provide advice and yet I was not able to do so as I was there only for research. This made me feel like I had gained what I'd needed from them and yet hadn't provided them with what they wanted and so it felt sometimes like an unequal trade off, and I felt as though it made me question myself as a healthcare professional. The dual identity of clinician-researcher was at times troublesome to reaffirm in my own mind to clarify my purpose and my objectives.

Upon reflection I thought about whether I had let these people down as they were hoping for dietetic input, for weight loss advice in one instance which the participant would benefit from in terms of health outcomes. That said, I was only able to see them in a research capacity.

4.15 Reflections on service provision- NHS versus private care provider

4.15.1 Dealing with patients with additional psychological support needs

Throughout my time as a long-term condition's community dietitian within the NHS my patient group consisted of newly diagnosed to severe COPD and heart failure patients. Through early reading in my PhD, I was aware of the association between diagnosis of one or more long term conditions and the correlation this had for a lot of people with poorer psychological wellbeing, in particular- depression and anxiety.

My working experience through my previous long-term conditions role in the NHS opened my eyes to see the extent of which these populations really do suffer from poor psychological wellbeing in terms of mood, motivation and grieving for loss of their former abilities. In my working experience, this was not something to be categorised, rather a continuum of which people would fluctuate in terms of severity dependent on other factors they were contending with in their lives and how much support they needed, had available to them and were happy to accept. This role made me realise as people begin to lose independence as a result of their debilitating, progressive condition, support and care may be available however, it can also be difficult for people to accept that help, and admitting they need support can be just as challenging to accept.

When I first begin my role within long-term conditions and began to engage with patients who had very low mood and outlook on their future, I met several people who expressed suicidal ideation. I felt thoroughly ill-equipped in how to engage in these conversations and communicate effectively and so I attended a training course. This course provided me with the understanding that providing people time to speak and feel heard was commonly a key factor in helping people feel valued and understood which in some can help to alleviate some of the emotional burden they are experiencing. This experience and skill development I have since carried with me in both my personal and professional practice.

In my professional practice, I continue to specialise as a community dietitian within the NHS at a different Trust and although I am not specifically working with only COPD or heart failure patients, people with these co-morbidities are regularly referred to our service. Other long-term conditions we regularly see, to name a

few, are cancer, neuromuscular diseases, cerebrovascular conditions and gastrointestinal long-term conditions. Within my role I carry out Dietetic assessment and develop care plans for these people once I have built rapport and gained an understanding of their everyday lives, their priorities, their barriers to change or daily challenges.

The key aspect is person centred care, as I may be assessing them for their nutrition but all the while someone is for example, in chronic pain and unable to mobilise to access food or in a deep episode of depression, a nutritional assessment and multidisciplinary care plan are required. For that reason, exploring what matters to the person most and assessing behaviour change motivation is paramount to treating patients holistically.

Working as a multidisciplinary team to provide the best possible care for people with long-term conditions, suffering for poorer psychological wellbeing and higher risk of malnutrition is key to provide support to community dwelling adults to prevent ongoing deterioration and adverse outcomes.

Throughout our training as allowed health professionals we are driven to signpost patients onto services that can help them. In my clinical experience, services for psychological wellbeing and stress which I have referred patients to following a dietetic assessment include but are not limited to smoking cessation, drug and alcohol support, bereavement counselling and clinical psychologists.

Our professional duty to "make every contact count" is part of our training and professional expectation within the NHS and contributes to the drivers of the NHS Long Term Plan to improve access to services for people suffering from ill-health (NICE 2020).

This knowledge and experience I carry with me into my role as a researcher in a similar population group of people with long term, debilitating conditions and perhaps naively expected the level of care and signposting process into relevant services to be the same within a private care provision setting. However, I was quite surprised to discover that this may not be the same across the board and it may either be a more complex or lengthy process to refer to different community services.

Several service user participants in my study had depression in their medical history and so upon my debrief meeting with CareCo managers and nurses I was intrigued to explore how this was managed in a private community care setting. To this question, I received quite a vague answer in that even if it may be identified

via initial assessment or annual reviews that these people are suffering from poor psychological wellbeing, the constraint on community services and referrals mean little is done. As such, the care provider will monitor them.

It is true to highlight that community mental health services are under immense pressure and waiting lists for people to be seen by specialist mental health teams and psychologists are ever increasing. Low mood or motivation is likely to limit access to food, food choice, food preparation, appetite and intake and association between poor mental wellbeing and lower BMI and increased risk of malnutrition in community dwelling adults has been well documented (Kvamme et al 2011; Gunduz et al 2015).

This therefore leads to question whether more can be done within home care provision to establish better multidisciplinary relationships between professionals in the community to make the referral process easier for people to access services who need it. Through early identification, assessment and prioritisation of need, service and resource efficiency and effectiveness could be improved, to best support this at-risk population through early intervention. I will explore this point in Chapter 6 in my recommendations.

5 Discussion

In this Chapter I will draw on the key findings of my research and explore these in line with other evidence. I will start by exploring nutritional care planning and draw on guidelines and policy as well as evidence to demonstrate the benefits of addressing nutrition in care planning. I will then discuss the potential for smart technology in this context. I then discuss healthcare ethics and explore autonomy versus advocacy as well as the role of family surrogates and consider the relation to decision making and care planning. I will then explore my dual-identity role and how that may have framed my data collection, analysis, and findings. This chapter seeks to expand on my findings in line with other evidence and serves as a bridge between my research findings in Chapter 4 and the implications they could have to drive change in clinical practice, in Chapter 6.

5.1 Summary of key findings

My ethnographic study revealed nutrition does not appear to be managed consistently within the home healthcare setting. Risk of malnutrition, dual burden malnutrition, sarcopenia and sarcopenic obesity were present in all cases and adverse effects were observed. Barriers to nutritional wellbeing exist due to lack of nutritional assessment to identify nutritional need, and no current training package for staff and carers regarding what constitutes to healthy eating or improving cooking skills. Low levels of awareness of nutrition was another key barrier from the care provider and carer perspective which again, is a consequence of nutrition as low priority and lack of nutritional training, education and awareness at an organisational level. Facilitators for nutritional wellbeing were patient autonomy, carer or relative advocacy and teaching carers how to prepare and cook preferred foods.

Within this context, nutrition did not appear to be addressed and there are guidelines and examples of how this might be done for improved outcomes which I would advocate CareCo to implement. I will later go on to

provide recommendations for future practice in chapter 6, but first I will discuss the complexities around managing nutrition in this setting which were also part of my findings, for example, ethical dilemmas.

5.2 Nutritional care planning

5.2.1 Importance of nutrition in planning care for patients with long term conditions

Specific guidance and case study examples of nutritional care planning in community dwelling adults with long term conditions receiving home care is scarce. For that reason, this section will present data of the wider context regarding the benefit of nutritional wellbeing in long-term conditions. Much of the evidence presented here originates from the NHS and NHS Frameworks. This evidence is still relevant as people cared for in the private sector will still receive NHS care, and high-quality care should be aspired to no matter the setting.

BAPEN recommend all commissioners, care planners and healthcare providers have a role to play within the integrated health and social care infrastructure which expands from individual health to care workers, local services, clinical commissioning groups and policy. Throughout this integrated infrastructure, BAPEN urge stakeholders to be responsible for making nutrition a priority, through identification and development of nutritional strategies across all conditions and healthcare settings (BAPEN 2020).

In 2013, the British Specialist Nutrition Association (BSNA) and the British Dietetic Association (BDA) released a thorough publication on the importance of implementing good nutritional care to improve the quality of life in people with long term conditions. That publication emphasised how dietitians have a significant role as the only regulated nutritional specialists to improve nutritional care in people with long term conditions and how this ‘can alleviate health problems, improve functional status, and increase quality of life and wellbeing’ (BSNA 2013). As discussed throughout Chapter 1, while we enjoy the benefit of medical advances that enable us to live longer, the consequence is that many of the older population live with multiple long-term conditions, rising costs of care as well as resource constraints. Therefore, there is an urgency for CareCo Healthcare to deliver improved patient outcomes meanwhile work effectively to relieve pressures on the health and social care sector financially. Through implementation of a robust nutritional screening tool to

identify those at risk of malnutrition and dual burden malnutrition within CareCo Healthcare clients, other needs of the client can be identified such as swallow ability, dexterity and food access. In turn, this would improve long term condition management and clinical outcomes through timely referrals to other community health teams such as occupational therapy and speech and language therapy. Repeat assessments through quarterly or annual review would help to identify clinical improvement or deterioration and ensure this is documented, improving condition management.

5.2.2 Improved patient outcomes when nutrition is prioritised in care planning:

The NHS Outcomes Framework revolves around 5 domains which are set to ensure NHS England are accountable to improving patient outcomes in people with long term conditions. The 5 core domains are as follows:

1) Preventing people from dying prematurely
2) Enhancing the quality of life for people with long-term conditions
3) Helping people to recover from episodes of ill health or following injury
4) Ensuring that people have a positive experience of care
5) Treating and caring for people in a safe environment and protect them from avoidable harm

Each of these domains are the basis of which each CCG is expected to fund their care on; however, each region and area are able to refine them on the basis of their local populations (BSNA 2013). As with evidence discussed throughout Chapter 1, these domains do not explicitly represent nutrition however it is implied and can be a proxy for each aspect. Each of these domains and nutritional supervision relate to my findings of case studies 1, 2, 3, 4 and 5.

The Health and Social Care Act 2009 provide regulations for care providers. The purpose of this act is to ensure people who are cared for my health and social care services “have adequate nutrition and hydration to sustain life and good health and reduce the risks of malnutrition and dehydration while they receive care and treatment” (Care Quality Commission (CQC 2020). It is interesting to note here that malnutrition is not

defined but could be interpreted as both undernutrition and overnutrition within this regulation. Sustaining life and good health could relate to both over and undernutrition through nutritional adequacy or quality. Meanwhile the latter part of the regulation implies priority to undernutrition by referring to malnutrition and dehydration.

The CQC go on to state that failure to meet this regulation which results in avoidable harm to the service user or if they are exposed to significant risk of harm can result in the care provider being prosecuted (Care Quality Commission (CQC 2020). Therefore, when we consider the findings of my results with 5 of the 6 case studies having nutritional need not met, it is important to consider what work can be done to ensure CareCo is avoiding potential risks to their service users. Both undernutrition and overnutrition here are of equal importance. I will now consider evidence for integrating nutrition in care planning and the human and financial benefits of doing so.

5.2.2.1 Evidence for care planning for malnutrition

Various regions have begun to implement nutritional strategies to improve patient outcomes within long term conditions. Here, I will present some of these findings to highlight the significant impact nutritional assessment and intervention can have for individuals and communities. The first case study focuses on the benefits of nutritional screening to identify malnutrition in care home residents. The second highlights the significant holistic improvements to health and wellbeing through provision of nourishing food to community dwelling adults who are vulnerable due to chronic illness or disability.

5.2.2.2 Peterborough: Improving Nutritional Screening in Care Homes and associated positive outcomes

NICE initially published clinical guideline 32 (CG32) in 2006 which was “Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition” (NICE 2006). CG32 outlines the expectation and guidelines for nutritional screening to identify those at nutritional risk and a pathway for action.

Within Peterborough community, following the publication of CG32, a prospective was commenced to improve the nutritional screening within six care homes with the aim to improve patient outcomes and reduce healthcare resource utilisation.

The project adopted a multidisciplinary team approach of care home managers, community dietitians, GPs and medicine management. Care home staff had training how to screen and sought to properly screen all residents (previously only 50 percent residents had been screened) and follow appropriate care pathways if risk of malnutrition was detected. They team collected data from the start of the project up until 3 months later to assess effectiveness.

The findings were:

1) Significant improvements in documentation of weight, height, proportion of residents screened
2) Appropriate use of care plans once residents had been screened
3) 31% and 27% reduction in hospital admissions and emergency department admissions respectively
4) 58% reduction in inpatient bed days of care per stay which is associated cost savings equating to a mean of £599 per person over 3 months

(NICE 2008)

The benefit to patient care, quality of life and healthcare resources demonstrated in this small-scale study are significant. Here, MUST screening and its usability after low-cost training with available readily resources (scales and a stadiometer) demonstrate how easily we can improve patient care and reduce burden on the health service if we make nutritional wellbeing a priority. This case study also highlights how the publication of new guidelines and policy are a key driver in changing care and improving quality care. Here, the work of a multidisciplinary team with a shared goal have sparked change and through those multidisciplinary relationships, have evolved the culture of nutrition in that setting.

This case study provides argument for nutritional screening in community dwelling adults to improve patient care, reduced hospital admissions and length of admission. It identifies the need to screen patients and follow care plans in order to optimise nutritional wellbeing. This is not current practice in CareCo Healthcare setting but has the scope to be a transferable and utilized to better manage nutritional need.

5.2.2.3 Hertfordshire Community Meals

Hertfordshire Community Meals (HCM) is a not-for-profit social enterprise which was founded in 2007 as a community led meals on wheels organisation. The Chronically Sick and Disabled Persons Act 1970 ensures there is legal obligation to provide meals for these population groups. Hertfordshire City Council contracted HCM to meet this obligation.

This community-based project serves 1800 nutritious meals every day to those living at home and to lunch clubs and offer a range of meals to meet cultural, religious and dietary requirements. Some of those who volunteered for preparing and delivering meals had been out of work. Between April 2011-12, a Social Return on Investment analysis was conducted. Of 1800 recipients, 613 people (34%) completed a customer satisfaction survey (although not all questions were completed by all respondents) and telephone interviews were conducted to help define outcomes and relative importance. 342 people (55%) felt better nourished because of the service, 130 people (21%) answered “sometimes” and 129 people (21%) did not answer. These proportions of results were reflected in the “I feel happier” answers. 193 people (31%) answered “always” and 128 people (20%) respondents answered “sometimes” to feeling healthier, have fewer injuries and visit their GP less because of the service (McCorriston 2016). Qualitative data from telephone interviews further highlighted benefits of the service. Respondents implied better quality of life and “Much happier now.” Client 6 “Very important service because I can't get out and about” whilst client 7 stated “If no hot food, wouldn't have bothered, health would deteriorate, slippery slope” which identifies the benefit to clients who are not motivated or able to prepare or cook meals for themselves.

Social Return on Investment (SROI) analysis is a method of cost-benefit analysis but incorporates sustainability and financial accounting (Social Value UK 2020). This therefore provides insight to the extent of which a project is beneficial not only in economic terms, but also socially and environmentally which is of increased interest in public health interventions. A SROI analysis was conducted on this project between 2011-2012 and estimated that every £1 invested yields £4.42 to £6.10 social return (McCorriston 2016).

The financial benefit of this service was estimated to have impact in 3 areas. SROI found reduced stress (and treatment for stress) for family members who are carers, reduced emotional burden meant increased time for family carers to work and cost saving to local authorities by supporting people to live independently reduced cost of residential care. The annual financial proxy in total for the latter two of these factors was estimated at £22,120 (McCorriston 2016). This is just one example of a community project of nourishing meal provision which has benefitted stakeholders socially, environmentally, emotionally and financially. Although the small response rate to the customer satisfaction survey was small which may pose risk of bias to results, from the feedback collected, it showcases the wider benefits of optimising nutrition at an individual and community level.

This case study provides insight to a method of community nutrition management in people with chronic disease or disability. Findings from this study present the wider benefits to individuals and communities which can be yielded through nourishing meal provision. It identifies that provision of one nourishing meal per day improved patient outcomes in feeling they had an improved quality of life whilst the financial analysis demonstrates cost-effectiveness in terms of social value.

5.2.3 Evidence for care planning in overnutrition

A report from The Lancet projects by 2030, there will be an additional 11 million people who are obese in the UK. This rise in obesity is forecast to cause an increase in long term ill-health, reducing health related quality of life which has impact at individual level but also causes societal loss to productivity, meaning economic and population impact (Wang et al 2011). This report made projections of which combined UK and USA

health risks associated with rising obesity. An estimated additional 6–8·5 million cases of diabetes, 5·7–7·3 million cases of cardiovascular disease and cerebrovascular accident and 492, 000–669, 000 additional cases of cancer are forecast. In addition, 26–55 million quality-adjusted life years lost have been estimated. Although these figures are combined and do not specifically estimate impact for the UK population, they identify an upsurge in long term conditions associated with overnutrition which requires attention and careful consideration for future health and social care strategy (Wang et al 2011). This highlights the significant need to raise the profile of optimising nutrition at a population level. More so, to contact meaningful overweight and obese patients, assess patient priority and encourage weight management health and social care practice.

Evidence of managing overnutrition within a home care setting is lacking which identifies the need for additional research to assess how the most effective way address this issue which will yield beneficial results. I will discuss this further in Chapter 6 when I provide recommendations for the potential of future care and additional research areas. However, evidence does show that patients with type 2 diabetes who achieve 10 percent weight loss within one year through diet and exercise lifestyle intervention reduce their risk of developing cardiovascular disease by 21 percent at 10 year follow up (The Look AHEAD Research Group 2016).

5.2.4 Financial impact of nutritional care planning:

5.2.4.1 Malnutrition

Nutritional support has been acknowledged as the third highest cost-saving intervention within health and social care, as £71,800 per 100,000 of the general population which is associated with the implementation of NICE Quality Standard Guideline CD32 (BDA 2017). On average, a poorly nourished patient will cost health and social care £5000 more to treat per annum than their nourished counterpart (Elia 2015). This highlights not only that nutritional care planning is worth investing in at an individual, population and organisational level, but also that implementation of guidelines and policy are the driver for change.

Further data analysis on nutritional assessment and care planning was conducted by Elia 2015 in the BAPEN economic report. Elia conducted a Budget Impact Analysis which presents a budget impact (net cost-saving) of between £63,192,501 to £81,870,330 for 80-90% patients at high risk of malnutrition who received oral nutrition support, whether that be through dietary counselling, food fortification or oral nutritional supplements. These cost savings identify that more needs to be done to take responsibility for nutritional screening in every care setting, to enhance quality of life and cost-saving to the health and social care system (Elia 2015).

The evidence for nutritional assessment and care planning and its benefit on patient outcomes has been discussed in the earlier chapters of my thesis. The evidence here presents an urge for commissioners to prioritise nutrition within care planning, highlighting the financial advantages as well as those to individual outcomes.

5.2.4.2 Overnutrition

The Lancet report on rising overweight and obesity levels also reported on estimated financial expenditure associated the increased prevalence of overweight and obesity by 2030. Medical costs associated with treatment for the expected new cases of obesity related preventable diseases (cardiovascular disease, cerebrovascular attack, cancer and diabetes) is £1.9-£2 billion for the UK (Wang et al 2011). Meanwhile, it has been estimated that preventing one percent adults from becoming overweight or obese could save the NHS budget £97 million per year (NICE 2014).

These studies and reports demonstrate the effect of nutritional wellbeing on social, physical and emotional wellbeing which contribute to sustaining quality of life in people who are chronically ill. They provide evidence of the importance of optimising nutrition to benefit human costs as well as financial costs to health and social care providers. The evidence presented here and in relation to my findings are the premise of my recommendations which I will go on to present and explain fully in Chapter 6. First, I will discuss the

potential of smart technology which was raised by Samira. I explore use of smart technology at present and consider how this could support nutritional care planning and management in the future.

5.3 The potential of smart technology for optimising nutrition

For most of the population, the use of technology has become ubiquitous to everyday life. The case of Samira demonstrated how smart technology is now being used for healthcare and medical purposes.

At present, robust evidence exploring use of Alexa or other voice recognition smart technology in long-term conditions is not available due to its very recent implementation. However, the Alzheimer's Society support McCann Worldgroup to design "My Carer" app for use in Alexa for people with early-stage dementia and those caring for them. It has been designed and advocated as a tool to help support patients to live as independently as possible, for as long as possible in their own homes. The app is designed to send voice notifications to remind the patient of a new task, for example to prepare lunch, take medication or remember a relative's birthday. By doing so, the aim of the app is to improve quality of life whilst promoting and maintaining connection of the patient with the world around them (Atkins 2019). There have been developments of the "My Carer" app. People with an Echo device which has a screen can now utilize an additional function of use of images and location to help guide tasks step by step, ensuring each step has been completed before verifying the task is complete (Little Black Book 2019).

The use of Alexa and voice recognition smart technology as a method of promoting selfcare and home healthcare is a recent development within community care. No evidence has yet been published which indicates whether patients and carers are experiencing positive effects of its use or not. The findings of my systematic review, meta-analysis and narrative synthesis in Chapter 2 showed a null effect of telehealth compared to face to face care in terms of quality of life outcomes. Meanwhile the qualitative findings highlight the patient voice in terms of concerns and benefits of digital health technology which demonstrates the need for further exploration and evidence in this area to allow clinicians to provide excellent care and allow patients to make informed choices about their care. Despite a lack of robust evidence, it does present

scope for potential healthcare innovation which could be utilized by people with a broad range of conditions or co-morbidity to support nutritional optimisation. Specifically, for patients or carers who are not confident with cooking, the impact of using visual or voice step by step guidance to support meal preparation could improve nutritional wellbeing and management within this context.

5.4 Ethical Principles in healthcare

Here I present the ethical principles of healthcare which should underpin all healthcare practice and provision. After providing definitions and brief discussion of each principle, I will continue to explore moral, legal, and professional conflicts which arise in reality within clinical practice, with relation to my research findings and other available evidence. The reason I discuss healthcare ethics is because of its interplay with decision making, food choice and meal preparation which framed the nutritional management in Thomas, Katie, James, Sandra and Samira's experience. I first present the ethical principles and later I go on to discuss them in context of autonomy versus advocacy and relate these concepts to my findings.

The term 'ethics' is derived from the Greek term 'ethos' which lends itself to meaning custom, character or disposition. At a simple level of interpretation, the meaning of ethics incorporates moral principles which guide individuals to make choices (Summers and Morrison 2009).

Principles of healthcare ethics are largely acknowledged as 4 main principles:

Non-maleficence meaning to 'do no harm' appears vague and dependent on the interpretation for what this means in context. This provides opportunity for different interpretations dependent on the viewpoint of the individual, community, or organization. In healthcare, 'harm' can occur in a broad range of circumstances; physically, psychologically, financially and through negligence, to name a mere few.

Beneficence originating from the Latin tern 'bene' meaning good. In healthcare we can interpret this to mean, 'be beneficial' which goes further than 'doing no harm.' Instead, this ethical principle embedded in healthcare culture requires a character trait or virtue to engage in an act to benefit others (Childress and Beauchamp

2001). The underlying expectation therefore is that people enter employment within the healthcare sector in the interest of helping people and as such, is written into healthcare professionals code of conduct and standards of proficiency. Active beneficence requires understanding everyone is unique, has worth and requires tailored treatment to ensure beneficence.

Autonomy refers to the Greek term 'auto' as in 'self' and nomos meaning 'rule' and 'law,' hence translating to the principle of self-ruling and deciding for oneself. In healthcare policy and guidelines, there has been a transition from traditional paternalistic care and greater focus on patient centred care to achieving quality care, taking into consideration patient values, wishes and concerns to offer the most appropriate care. Dominance on this principle of healthcare ethics has come under scrutiny over the years with controversial opinions over how much power should be attributed here, especially if it conflicts with the other ethical principles. Evidence of moral, legal and professional conflicts felt by clinicians at the liberty of patient autonomy are well documented (Dzeng et al 2015).

Justice refers to 'fair treatment' which within healthcare is based on the distribution of healthcare services, equity of access and rationalised by clinical need. Reports from the British Medical Association explain the principle of justice in terms of health care rationing, and six proposed 'need principles' based on a range of factors which include threat to life, cost to benefit degree of immediate or ill health. To maximise principles of justice, clinicians are required to ensure healthcare is distributed and provided in a way which will yield the best possible consequences, in an impartial and verifiable approach to ensure equitable treatment for all (Cookson, Richard, and Dolan 2003).

5.4.1 Autonomy versus advocacy in relation so healthcare ethics

All healthcare workers have a legal and professional duty of care outlined in their code of conduct which stipulates healthcare workers should promote good quality care in patient interest, reduce risk of harm and refrain from maltreatment, meanwhile respecting patient autonomy (Royal College of Nursing 2020).

However, as my findings highlight, within healthcare ethics, there must be a balancing act between the dominance attributed to each of the principles.

In case study 3 I presented my time with James who is being accompanied by a CareCo Healthcare member of staff every day to get a takeaway for lunch. He is physically free and able to do this and can communicate his choices openly and so having care assistance complies with patient autonomy. Nevertheless, his condition requires nutritional control and portion regulation of certain food groups, as well as the need to maintain a healthy Body Mass Index (BMI). Thereby, under healthcare ethical principles I struggle to comprehend how this is an acceptable act of 'care' which adheres to *non-maleficence* given his weight gain, and likely cause for his new diagnosis of a long-term blood glucose condition, heightened by cardiovascular risks associated with increasing BMI. In James' case, given his character to be described as 'difficult to manage' by CareCo Healthcare staff, it appears that patient autonomy has over-dominated other fundamental principles of healthcare provision.

In a similar nature, a senior clinical researcher, Woodward encourages caution to be taken when providing overemphasis on patient autonomy. She warns how this may obscure and overpower beneficent interventions, and ultimately if that results in harm being caused to a patient by act or absence of acting, then professional and legal obligations remain unfulfilled (Woodward 1998 cited in Hyland 2002). This is a stark reminder of the moral and professional duty of care expected.

To build on this, a question I asked myself time and time again regarding James' case is: who is advocating for James to make better choices and is it morally right to do so? I was interested to find publication of a similar case from a nurse specialist which resonated with me regarding James and the care is receiving. Hyland 2002 conducted an ethnographic study to explore the relationship of autonomy versus advocacy in nursing practice whilst she was employed as a clinical nurse manager on a surgical unit. Within her reflections she asked "*Should a nurse caring for a diabetic patient advocate for his or her right to eat whatever he or she wants, regardless of the consequences, or should the nurse endeavour to ensure that the patient complies with dietary restrictions? In such a situation there is obvious conflict between the nurse's duty of care and the advocacy role, particularly if one accepts that the nurse should promote the patient's right to exercise autonomy, even while disagreeing with the patient's choice"(* p473-473). This highlights the moral conflict

felt by clinicians when deciding clinical care, meanwhile illuminating that more needs to be done to ensure provision of quality care (Hyland 2002).

In diabetes we know risk of complications and progression can be prevented through good quality diet, physical activity and weight loss (NHS 2018). We also know consequences of unmanaged and poorly controlled blood glucose will inevitably require medical management, either oral, or injections of insulin. The associated financial cost of in type 2 diabetes in the UK is currently exceeding £6 billion per annum constituted of social cost, medication and monitoring (NHS 2018). This is aside from human cost to quality of life. Is this a moral path to assist a patient down, quite literally in James case? The ramifications of poor blood glucose levels on the body (made worse by poor diet quality and weight gain) include risk of cerebrovascular attack, myocardial infarction as well as diabetic neuropathy, nephropathy and retinopathy, and the correlation and causation of these are well documented (Sami et al 2017). Certainly, the fact that his care plan states regular checks of his blood glucose levels should be taken and it transpires this is not happening, there is definite cause for concern. Identified here is significant scope for improvement in care planning and careful monitoring of care plans which have been implemented to ensure objectives are being achieved. Indeed, work from McParland et al (2000) identify how absolute obligation to respect patient autonomy can prove problematical if it causes conflict with professional obligation and hence moral self-governance of healthcare professionals (Hyland 2002).

We compare the case of Sandra in case study 4, who has also gained weight over the years which has been noticed by staff. Sandra's is a permanent wheelchair user and is without the physical freedom to walk to the shops and action her wishes unlike James. She can verbalise her wishes to her care team and yet, the foods she asks for is being restricted due to her weight gain. Rhonda is acting as her advocate, to try and encourage weight loss as she is aware of the benefits, therefore one could assume advocacy is an act of beneficence. However, these restrictions have led to Sandra to hide foods in skin folds and private areas which is potentially harmful (maleficence) and against patient autonomy which subsequently conflicts with healthcare ethics. It is interesting to compare the two different cases and consider the ramifications of the action (or lack of) from CareCo Healthcare and how this relates to both duty of care and ethical principles of healthcare. Sandra's case highlights the need for a dietetic referral and specialist assessment and care planning which is

currently lacking. Although Rhonda is acting as an advocate and trying to promote healthier behaviours, categorising foods as “forbidden” is not recommended and has led to potentially harmful behaviours in attempt for Sandra to conceal food from care staff.

The disparity between cases highlights inconsistency of care and call for action to identify a more united standpoint or clinical reasoning for either autonomy or advocacy. Martin (1998) presents an interesting point when considering ethics of healthcare practice that ‘*for empowerment to exist, nurses need both a managerial structure and an educational process that supports and encourages the development of the essential attributes necessary to facilitate the empowerment of patients.*’ This resonates with the cases presented and supports the needs for training and education to be valued from an organizational level to be implemented and cascaded down for patient benefit.

With consideration of the above case studies, a need for making informed health choices is highlighted. A key skill and fundamental role of dietitians’ is motivational interviewing. Motivational interviewing is an evidence-based, patient centred counselling approach for eliciting health behaviour change through exploration of barriers and drivers for behaviour change in a non-judgmental space (Madson, Loignon and Lane 2008). Following identification of adults at risk of malnutrition and dual burden malnutrition, dietetic consultation and use of motivational interviewing may help to alleviate ongoing modifiable dietary risk factors in each of these clients. Further, for CareCo Healthcare to ensure high quality care is provided and best practice guidelines are being adhered to, documentation of client choice and capacity to make informed decisions should be documented, in line with CQC Guidance for Care Providers (CQC 2005). In order for staff to make decisions in best interest, dietitian led training on nutrition and hydration to improve the knowledge, awareness and culture of nutrition within CareCo Healthcare is required.

In summary, these cases highlight the need for implementation of a nutritional risk assessment and referral process to dietitians for patients who require specialist input, as well as training and goal planning opportunities to manage nutrition. Through dietitian led training of staff and improved culture of nutrition within CareCo Healthcare, those patients identified as low to medium risk of malnutrition and dual burden malnutrition could be supported by CareCo Healthcare staff to make healthier, informed choices regarding nutrition and hydration. Meanwhile, those identified as high risk would be referred to local community

dietetic services. Nutritional assessment and an action pathway would mean client care is standardised and regulated which would help to alleviate such disparities currently experienced between care packages, particularly in the area of overnutrition and dual burden malnutrition as identified in my findings.

5.4.2 Family surrogates in decision making of care

During my results I presented findings of family dynamics and the role that had in management of nutrition. For clarity, when I discuss the role of the family member here, I will refer to them as family surrogates as that is the ascribed term in existing literature. A family surrogate is typically someone who acts on behalf of a patient who lacks capacity or is unable to speak for themselves to provide direction in decision making based on the patient's preferences, beliefs or values (Sabatino 2018).

Challenges and benefits of family surrogate decision makers are apparent in my findings. Families engagement in decision making and care implementation was found in Katies case to be beneficial to nutritional care, whilst in Sandra's case, family decisions and values conflicted with those of the care provider and were detrimental to treating overnutrition and managing risks of dual burden malnutrition and sarcopenic obesity. Evidence of family surrogates and their engagement in care planning with long term conditions is lacking. Here I present existing literature of family surrogates in acute decision making and consider what learnings can be derived from available evidence with understanding of contextual differences.

The Cancer Pain Relief Committee released a compelling case report which presents the complexity of decision making when family surrogates values conflict with clinical justification or patient preference. This case report illuminates the challenges in navigating this position to ensure safe and consistent implementation of a care plan or clinical decision. Given the challenges of autonomy versus advocacy, it has been documented that these issues are heightened if surrogates project their values or wishes onto a patient. Moreover, sensitive communication should be utilized if a surrogate asserts unlimited decision-making autonomy (Fine 2010). Within Sandra's case, this situation was highlighted in the altercation between Sandra's mother and Rhonda, whereby Sandra's mother appeared to assume ultimate autonomy. Issues of healthcare professionals no longer

working with Sandra appears to be a result of this which is worrying in terms of care quality. In contrast, where Steph has exerted an extent of autonomy in advocating for Katie's care, this concept appears to be beneficial as Steph oversees care daily and has built good relationships with the care team. Therefore, it seems family surrogate decision makers can be both beneficial and detrimental to achieving quality care in long term conditions, but shared decision making processes should be adhered to (including the patient, clinicians and care provider) to ensure safety (NHS England 2019). As this is does not appear to currently be happening within the CareCo Healthcare context, I have included this in my recommendations in Chapter 6.

A systematic review of qualitative studies on the experiences and perspectives of family members as decision makers was conducted (Su, Yuki and Hirayama 2019). This review included 24 studies and 637 participants of family surrogate decision makers in hospital, care facility and community care setting, participants were predominantly female. 10 studies investigated end of life care, 7 explored intensive care and 7 were focussed on the decision of a long-term care placement (such as a nursing home). The Joanna Briggs Institute (2017) Critical Appraisal Tool was used to assess methodological quality however reporting on the quality of included studies was missing. Thematic synthesis was to summarise existing literature (Su, Yuki and Hirayama 2019).

Key themes derived from this synthesis are as follows; struggle and reluctance, seeking reassurance, communication with healthcare professionals, family support, older adult wishes and negative impact. Although all these outcomes are important, I will discuss communication with healthcare professionals and negative impact in more detail as they relate to the findings of my study.

This synthesis found that usually, inexperienced surrogates trusted healthcare professionals in the decision-making experience and when people felt there was adequate communication and support available, this alleviated some emotional stress. A common issue raised in this theme was that poor or unclear communication led to dissatisfaction and made decision making more burdensome for surrogates. Confusing communication stemmed from lack of time of healthcare professionals or care providers (Su, Yuki and Hirayama 2019). These findings are from surrogates who have been heavily involved in making a specific decision rather than ongoing care however they highlight issues which are relative to that context. In Katie's case, Steph felt communication was lacking from the care provider which led to her feeling inadequately

supported when trying to ensure Katie had consistent care. Again, this strengthens the argument for shared decision making, to ensure effective communication and safe implementation of care plans (NHS England 2019).

In terms of negative impact, this synthesis found family surrogates experienced emotional and physical burden. Emotional burden was commonly associated with uncertainty of the decision made and whether it was best for the patient which resulted in grief, anxiety, guilt and helplessness. These feelings appeared to be exacerbated if there were conflicts between themselves and the clinician or other family members regarding decision making. Experiences of weight loss, depression and fatigue as a result of disruption of their usual routine were attributes of physical burden (Su, Yuki and Hirayama 2019). These results are not transferable, but they do highlight factors which appear to resonate to an extent with the experience of James' wife who is involved in James' daily care. She has suffered from depressive episodes and will also likely be involved in future decisions of whether James has a PEG tube inserted for feeding.

Overall, it appears that family surrogates in healthcare decisions can be both beneficial and detrimental as identified in Katie's case compared to Sandra's. The evidence presented here presents complexities in making acute decisions rather than long term care planning. However, the highlighted factors which were relative to my findings support the need of effective communication between all parties to ensure care is patient centred and decision making is a collective process (NHS England 2019). It is implied that this will help to relieve emotional and physical burden experienced by surrogates and improve knowledge transfer between clinicians, patients, and surrogates. There is need for shared decision making and patient centred care which I will discuss in my recommendations for future practice in Chapter 6.

5.4.3 Care planning and financial security

I have considered various findings of my research in line with other available evidence and principles in healthcare ethics. I now feel it is important to highlight and comment on the inescapable financial connection

which exists between CareCo Healthcare and the client and the power relation which this inevitably entails. I relate this to patient autonomy versus advocacy and how that played a role in management of nutrition.

I presented cases of Katie, James and Sandra, each of whom had experienced varying levels of power battles with CareCo Healthcare. Katie's case is the only one I observed where her family had pursued CareCo Healthcare to promote staff and provide training, of which CareCo Healthcare obliged. In James' case, I felt there was an element of apprehension in encouraging change in the branch nurse expressed the "fear of being too pushy and losing the client." Meanwhile, I observed the strained dynamic between Sandra's family and carers and questioned why in each of these cases, there was no motivation or initiative taken to meet the needs of the individual or review the care plan.

In Chapter 3 I provided brief insight to recent financial hardships CareCo Healthcare have faced, which requires a deleveraging and re-financing the entire organisation. I then question the extent of pressure which exists among the organisation to retain long term complex care packages (which can generate a huge annual income) and how to an extent, that frames engagement and decision making between clinicians and clients. These constraints were echoed in James' case in discussion with the branch nurse who commented on the "fear of the care provider being too pushy" which could result in losing the client. This therefore supports the complexity of decision making, especially when there are inescapable financial relationships and the role that plays in autonomy versus advocacy discussed in the previous section of this chapter.

5.5 Dual identity: clinician-researcher role

I previously presented examples of moral conflict I experienced throughout my time in the field which I will now build on along with exploration of available evidence from experiences of other clinical researchers. Many health researchers are clinicians by background. Nursing research dominate the field of clinician

research. The dual role we clinicians must adopt bring about conflicts which I needed to plan for, attempt to manage and navigate my way around throughout the research journey to produce methodically and ethically sound research.

My clinical role, specialist knowledge and training to provide quality patient care is ingrained within me and it is not possible to get away from that to completely adhere a researcher role. It will have inevitably framed my interactions with patient-participants and healthcare professional-participants.

I presented earlier the tension I felt when a patient-participant directed me a clinical question which I had the skills and knowledge to answer. In that instance, I reaffirmed my identity and purpose as a researcher and the boundaries that role entails as I judged it as potentially problematic to begin giving advice. Colbourne and Sque (2004) report in their paper on nursing and nurse researcher roles how answering clinical queries did not trigger these internal conflicts and instead, they felt able to answer without fear that it would invalidate the research process. Whereas Sword (1999) reflected on feeling morally and ethically conflicted, wanting to provide health information advice to low-income pre-natal mothers but uncertain if this would hinder data collection and quality. The account of Sword (1999) resonates with my personal battle between professional and ethical codes of conduct as I too was cautious not to blur boundaries of my research role. Blurred roles and risk to data quality is echoed in a recent narrative review of clinician researcher experiences of conducting healthcare research (Hay-Smith et al 2016). This illuminates ongoing, significant controversy of dealing with conflict within clinical research roles. Meanwhile, it presents the point that each dual-role experience is personal, unique and context specific and as such, should be managed accordingly.

5.6 Strengths and limitations of this research

5.6.1 Ethnographic methods

In Chapter 1 I introduced ethnographic research methods and explored some of the limitations which can be attributed this method of research in terms of lack of reporting guidance and ambiguity in obtaining informed

consent. Here I will discuss my experience of conducting ethnographic research and the strengths and limitations of this research as result of ethnographic exploration.

Prior to commencing this study, understanding of the culture within people with long-term conditions in a home care and nutrition in this context, was lacking. The strength of ethnographic methods here is the level of insight it allows through active engagement within the context to speak to participants and collect data through conversation. More so, of potentially greater value, is the opportunity for observations and reflections of these using new insider knowledge whilst drawing on existing knowledge. The flexibility of ethnography to enable the researcher to immerse themselves within the field allows for rich data collection and meaningful analysis. For example, if I had used semi-structured interviews only, I doubt I would have been able to report findings which truly reflect the culture or context of nutrition in these participants experiences, as data would not have been triangulated with active immersion.

Further, in my experience, use of purposeful conversation and documentation of jottings and fieldnotes seemed to work well with participants in this study. Purposeful conversation meant interactions seemed to flow freely which helped with rapport building which I feel then improved the openness of conversation whilst having a topic guide enabled me to probe for additional information in nutrition or mealtimes without me leading the conversation. The data I collected from free-speech which occurred from these conversations I may have missed if I had adopted structured interviews, for example that James could not smell or taste food and selected his meals based on memory of his preferences prior to his incident. This transpired to be a key finding which significantly impacts his nutritional wellbeing and demonstrates the value of ethnography and open conversations in a setting where participants feel relaxed and comfortable.

A limitation of jottings and fieldnotes during purposeful conversations and observations is the risk of missing data or not documenting aspects of potential relevance. It is true that this may have occurred as I chose not to audio-tape conversations which may have helped to capture all verbal data. I decided not to do this as I felt it may pose risk to how comfortable people felt to speak to me if they were being recorded which would have been a visible barrier also. My experience in making jottings and notes throughout assessment with people in their homes in my NHS role, whilst engaging in conversation was a beneficial skill to have throughout my time in the field which to extent, reduces the potential of this limitation.

Overall, despite controversial opinion of the rigour and use of ethnography, it seemed the most appropriate methodology to answer my research question. I have been able to learn the perspectives of the individual, carer, and care provider to understand more comprehensively how nutrition is managed in people with long term conditions receiving home care. I have been able to develop understanding of the current barriers and facilitators to nutritional wellbeing in this setting and gained insight to the culture within the setting which is what I set out to achieve.

5.6.2 Industry funding

This research was partly funded by my university and partly funded by CareCo Healthcare, and here I will address the potential implications that may have had on the data I did or potentially did not collect, and how that may have shaped my findings. Both funders for this research area had incentive for supporting the project, either academic or financial in terms of service improvement. However, I do not wish to overstate this as a great limitation of my research as CareCo Healthcare and my university were very supportive of my line of enquiry and research methods. Following my systematic review and meta-analysis I realised that there was seldom published research focussing on nutrition in this setting and context. I realised I needed to work backwards to explore the current practice and gain insight in context to understand the barriers and facilitators to nutritional wellbeing within continuing home care. At this point, I was in contact with a gatekeeper at CareCo Healthcare who enabled my pairing with a CareCo Healthcare branch. Had I been partnered with a different CareCo Healthcare branch in a different location, my findings may have been significantly different to the ones I present here.

Once I was paired with a CareCo Healthcare branch, I had initial phone calls, emails, and meetings with staff about my research aim and objectives. I was reliant on support from the CareCo Healthcare team to identify potentially relevant participants, as I has no prior involvement with CareCo Healthcare or their clients. As stated in Chapter 3, I requested access to a database which would provide me with a breakdown of clients and their conditions however, I was told this did not exist. Therefore, participant recruitment was reliant on branch

managers and nurses in terms of identifying potentially. It is possible therefore, to an extent that CareCo Healthcare framed my line of enquiry and the participants I had access to, however it was my only option and I trusted their inside knowledge of their client base.

5.6.3 Dual role

I have tried to be as reflexive as possible throughout my project and presentation of data and findings, but it is crucial to highlight my identity and how that may have shaped how much or little I was able to collect. Indeed, to build on this point, my own interests, previous experiences, and knowledge would have framed what I found of interest and what guided my line of enquiry. My dual-role experience which is likely to have also framed interaction with participants is that fact this research is partly funded by CareCo Healthcare, the care provider for patient participants and employer of staff participants. In a sense, my identity and intentions are likely to have come into question, despite my attempts to be transparent throughout. This may be perceived as both a strength and a limitation to my study. My prior professional experience working in a similar setting, my understanding for care provision and communication with patients, carers and healthcare professionals enabled me to build rapport within the field. This was of benefit to the study as rapport building was what enabled me to collect rich data. Further, I have been able to reflect on these with depth due to my professional training, consideration for holistic patient care, multidisciplinary team working and the wider context of health and social care.

My prior knowledge, insight and understanding of long-term conditions and healthcare practice means I have been able to relate to patient participants as well as clinician participants. It also means I have credibility when relating to and working with other clinicians to make recommendations, acting as a hypothetical bridge between the research world and healthcare practice. However, given my prior knowledge of long-term conditions and a community care setting, it may mean that I had prior assumptions when entering the field or

felt I familiar with the context of home care. This may have led to lack of documentation on aspects which were equally relevant. To reduce this, I continually reflected on my practice and thoughts throughout my time in the field and have presented these reflections throughout.

When I consider my role in this project, I feel it important to state as much as I have attempted to spend time with participants to build rapport and gauge in depth, true insight and understanding of their lived experiences, I do not wish to overstate this either. Here it is important to emphasise that only the participant truly knows their view truly, and what I present in this thesis are accounts of what participants allowed me insight to presented through my lens as a dietitian and novice ethnographer.

Despite internal and potential external conflicts experienced resulting from my dual role, I do not wish to overstate or exaggerate a notion that dual role identity is entirely problematic for conducting healthcare research. Rather, I present a compelling counterargument for the ongoing need for clinicians to lead research enquiry as a driver of pertinent and innovative healthcare and service development and therefore view dualism as a strength in innovative healthcare research. An example of the benefit this brings is when we consider identification of areas lacking understanding, such as the present study. A historical example is that of the association of substance abuse and psychological illness which was not understood until clinicians highlighted it as an area requiring in depth inquiry to determine appropriate service provision (Pepper, Kirschener and Ryglewicz 1981).

6 Implications for clinical practice

6.1 Bridging the gap between research and practice

It has been documented that within healthcare, there is a fundamental lag time between healthcare research knowledge generation and time to implementation or change clinical practice (Nicolini et al 2007). I will explore some of the reasons for this here and hope to illuminate the value of this research and research design to emphasise how these results can help to drive significant improvement in service delivery.

A crucial topic, often examined with consideration for facilitating innovation or improvement, is the need for knowledge embedded within one community, context or setting, to become available or recognized to others within a different community. Brown and Duguid (1991) and Wenger (1998) conceptualised that practice knowledge is learned through study of a specific social context however, present the notion that individuals who are not familiar with, or members of, a given social context are likely to ascribe a different meaning or understanding to a specified knowledge set, interpreting it instead with their predisposed assumptions. A review of the literature in translation of knowledge in healthcare was conducted. This critical synthesis of existing literature identified this can occur intentionally, or not, dependent on the motivations for the study, by whom it is being studied or funded by and indeed the associated cost: benefit risks involved (Oborn, Barrett and Racko 2010). To an extent, this is relatable to the findings of my study in that I had some prior knowledge and experience of working in a similar remit.

In more recent years, the concept of successful knowledge generation and translation has been depicted and globally acknowledged via various models. The models recognise the need to address the research- practice gap, through knowledge exchange between stakeholders, reshaping how knowledge, power and identity are intertwined and appreciate the need for involvement of all parties. Baumbusch et al (2008) proposes knowledge translation through conjoining both academically based and clinical based researchers present opportunity for successful implementation of results, appreciating expertise from both sides (Oborn, Barrett and Racko 2010). This proposed approach to knowledge translation was developed from the learnings of

previously funded ethnocultural research by the Canadian Institute of Health Research which was following patient journeys from hospital to home.

Regarding service redesign, development, and improvement, I fear the above opinion lacks the voice and expert knowledge of the client, carer or care provider which is essential for appropriate and successful implementation and adherence to truly produce research with impact. Indeed, in more recent years knowledge transfer between client and clinician has been acknowledged as a process required for shared decision making about treatment of chronic disease, recognised as gold standard within healthcare practice (Desroches 2010). This explains why the research I present here has clinical significance. It presents complex knowledge construction and through inclusion of and triangulation of a range of data, rather than inclusion of merely one knowledge viewpoint, interpreted with by dual-identity of an academic-clinical researcher. My dual role has been advantageous to bridge the gap between the field of research and healthcare practice in order to make innovative, relevant and useful recommendations.

6.2 How can these findings translate into healthcare practice? Research through the dietetic lens

My role and identity as a dietitian have guided my line of inquiry throughout this project and here, I will now focus my findings and concepts of my discussion through my dietetic lens. First, I will introduce the role of a dietitian. Registered dietitians are the only regulated nutrition professionals with a protected title, standardised by a governing body, the Health and Care Professions Council (HCPC). Dietitians are uniquely trained to conduct thorough nutritional assessment, diagnosis and treat diet or nutritional problems both at an individual and societal level. To practice as a registered dietitian and meet standards of conduct, dietitians must stay updated with research in public health, medical and scientific fields which relates to diet, disease, and health. This knowledge is translated into clinical practice and practical guidance to educate and enable people to choose appropriate diet and lifestyle behaviours (British Dietetic Association 2020).

Based on research studies and examples of best practice drawn from across England, the devolved nations, and internationally, this report highlights the economic and clinical benefits of providing good quality nutritional care to people with long-term conditions.

It is intended for local commissioners, including clinical commissioning groups (CCGs), healthcare professionals, policymakers and wider stakeholders who have an interest in improving the quality of nutritional care. It also makes a number of practical recommendations for NHS England, commissioners and providers as to how the NHS can prevent health complications, as well as improving the quality of life for those with a long-term condition through nutritional care.

6.3 Alpha Food- CareCo Healthcare subsidiary

As with other names and identifiable data within my thesis, the actual name of CareCo Healthcare subsidiary has been replaced by a pseudonym, protected for legal purposes. However, the content and information I provide here explores how a daughter company within the large organisation, is specifically focussed on food and nutrition.

Alpha Food is a subsidiary of CareCo Healthcare, and their partnership is publicly published. Alpha Food claims to deliver ‘best-in-class’ food and scattering services to a broad range of settings including corporate catering, schools, and hospitals within the UK. Alpha Food has engaged in a range of pledges to improve access to healthier food and improve availability and consumption within the UK and in schools, meaning it is one of 15 companies to adhere to the commitment which commenced a few years ago.

Within Alpha Food, there are employed nutritionists as well as chefs and catering staff. Several published statements are publicly available from Alpha Food Nutritionists and Heads of Procurement which explain the commitment of the company to source nutritional ingredients because of the wealth of known benefits good nutrition has on their clients. Of particular interest to my thesis, is that claim from Alpha Food of the huge role

nutritious food has for good recovery, wellbeing and comfort to patients. Further, that individual clients in a range of settings should be supported nutritionally.

Given the human benefits and cost benefit of recognising nutrition within a care plan, the realisation CareCo Healthcare own Alpha Food is inspiring. The magnitude of impact that the staff from Alpha Food could have on patient care and carer training within CareCo Healthcare could be far-reaching. Alpha Food has skilled chefs, catering experts and nutritionists. If there was scope for a collaborative project, the direction of future services could change hugely through raising the profile of nutrition and understanding among staff and result in improved nutrition management within this setting. If it is identified through an initial assessment that a client requires support to prepare or cook nourishing meals, CareCo Healthcare could draw on the resources and skills of Alpha Food staff to provide training for carers. This may help to provide carers with confidence in food preparation, meanwhile increase knowledge and awareness of what constitutes to a balanced meal.

6.4 Potential for a new clinical pathway within CareCo Healthcare

My findings and discussion have emphasised the need to raise the profile of nutrition within CareCo Healthcare culture and the explicit need for nutritional assessment upon commencing a care package. I have presented evidence to support this in terms of patient care, quality of life and financial benefits in Chapter 5. In this Chapter, I would like to introduce my vision for a detailed screening tool which can be used by CareCo Healthcare staff upon meeting a potential new client, at annual reviews of current clients who have not been nutritionally assessed, and at their reviews thereafter.

This clinical assessment captures an abundance of data which will guide staff to identify whether there is nutritional need, contributing factors and make an informed, holistic care plan. This pathway also empowers staff through providing an accurate and thorough form of documentation to monitor patient health and easily identify a change to health which may pose risk and require investigation or care plan modification.

My motivation for developing this tool stemmed from my findings and realising that at present, there is very little nutritional awareness and it remains a low priority in care planning for people with long-term conditions who are receiving home care. The lack of nutritional care planning is the result of no formal needs assessment to incorporate nutrition upon commencing a care plan. As stated in Chapter 1, the MUST screening tool is inadequate to screen patients with long term conditions as there is no category which allows for chronic disease to be specifically risk assessed. Therefore, the assessment tool I have developed and present later in this Chapter is a progression of the MUST tool to incorporate assessment and acknowledgement of dual burden malnutrition and long-term conditions, given their implications on nutritional status, as discussed throughout my thesis. Given my dietetic training, knowledge and experience I am keen to implement a user-friendly assessment tool which can be completed by CareCo Healthcare to prevent nutrition being overlooked in the future, with the view to optimise holistic care in managing chronic disease. Unlike the MUST tool, my nutritional screening form identifies wider aspects affecting nutritional care, ensuring social, psychological, physical and environmental factors are identified such as food access, ability to feed oneself and mood. This is a comprehensive method of screening to enable CareCo Healthcare make further referrals to local services, if required, to ensure holistic management of community dwelling adults with chronic disease receiving homecare.

6.4.1 What this clinical pathway could look like

Figure 27 presents a nutritional assessment tool for implementation in the CareCo Healthcare home care setting, based on my findings. This tool is designed to be used for both over and undernutrition. Within initial assessment, there is space to document current weight and height to calculate BMI (which gives crude data on how well nourished a person is). This assessment encourages the care provider to investigate weight at initial assessment as a crude measure of nutritional wellbeing. It prompts calculation of weight change, whether that is weight loss or weight gain. Either of these will require additional investigation to understand the aetiology of that weight change. You will see included, identification of clinical factors which may contribute to malnutrition (over and undernutrition), within clinical factors is assessment of physical function (falls and

frailty) which can imply poor nutrition. Finally, you will see assessment of social factors which should help to guide the care provider to address any barriers at an early stage of care planning to ensure a holistic care plan is developed which adequately addresses patient need. Unlike the MUST tool, this assessment form builds on the findings of this research in line with existing literature and prompts evaluation of a broader range of factors which can contribute to malnutrition.

The tool is designed to be user friendly, with scope for it to be used at annual reviews so that reviews can be easily comparable, and progress or deterioration can easily be identified. It has been purposefully designed to probe for information which will assess whether a client has additional unmet nutritional needs which may then indicate additional services should be involved in developing the care plan. For example, if swallowing difficulties are noted, this may be indicative that Speech and Language Therapy should be involved. If the client is unable to prepare food, cut food once it is in front of them or adequately feed themselves food or fluid, this will indicate occupational therapy could provide support. By completing this assessment, how a patient presents as baseline can be clearly documented which then helps to assess what is "normal" for that individual which will be helpful and safe practice if there is a change in staffing on a care team. Through having baseline information documented, it will be easily identifiable upon review if the client is stable, declining or progressing and the care plan can be then modified, based on the values and goals of the patient.

I have included space for client set goals at the top of the tool so that they are easily identifiable to any member of staff, the client or carer who may use the tool, at any time. The aim of goal setting provides opportunity for the client, care staff and care provider to work comprehensively to achieve a goal which is a priority to the client with support from the care provider, adhering to patient centred care (The Kings Fund 2012).

Figure 27: Nutritional Assessment Tool

Client name:	
DOB:	
Hospital Number:	
Address:	
Safeguarding risk?	Yes ☐ No ☐ If yes, please provide details:
Able to communicate?	Yes ☐ No ☐ If no, please provide details:
Client goals	

ANTHROPOMETRY	Date	Weight (kg)	Height (m)	BMI(kg/m²)	
	Previous dates:				
	Weight change:				
	MUST on initial assessment: Date:	0 ☐ ☐	1 ☐	2 ☐	3 ☐ 4
	MUST on review: Date:	0 ☐ ☐	1 ☐	2 ☐	3 ☐ 4

CLINICAL	Presenting complaint:		
	Long term condition:	Yes ☐	No ☐
	Dementia:	Yes ☐	No ☐
	If yes, please state severity/ type:		
	Frailty:	Yes ☐	No ☐
	If yes, please state severity:		
	Falls	Yes ☐	No ☐

	Does this person have capacity?	Yes ☐	No ☐
	Swallowing difficulty:	Yes ☐	No ☐
	If yes are SLT involved?	Yes ☐	No ☐
	If no, has a referral been made?	Yes ☐	No ☐

ADDITIONAL CLINICAL FACTORS	Gastro	Yes ☐	No ☐
	Bowels (i.e diarrhoea/constipation/stoma care)	Yes ☐	No ☐
	Burns	Yes ☐	No ☐
	Cancer	Yes ☐	No ☐
	Diabetes	Yes ☐	No ☐
	If yes, please specify:	Type 1 ☐	Type 2 ☐
	Is this client insulin dependent?	Yes ☐	No ☐
	Renal (kidney) impairment	Yes ☐	No ☐
	Liver disease	Yes ☐	No ☐
	Respiratory (lungs) or cardiac (heart) condition	Yes ☐	No ☐
	Psychological factors	Yes ☐	No ☐
	Dietary barriers (low appetite/food aversion)	Yes ☐	No ☐

SOCIAL	Able to safely cook for self	Yes ☐	No ☐
	If no, please state plan to meet care need:		
	Appliances available to safely store and cook food	Yes ☐	No ☐
	If no, please state plan to meet care need:		
	Able to do food shopping	Yes ☐	No ☐
	If no, please state plan to meet care need:		
	Independent with eating and drinking	Yes ☐	No ☐
	If no, please state plan to meet care need:		

Follow up assessments

Have there been weight changes since last assessment?	Yes ☐	No ☐
If so, please provide details:		
Have there been clinical changes since last assessment?	Yes ☐	No ☐
If so, please provide details:		
Have there been social changes since last assessment?	Yes ☐	No ☐
If so, please provide details:		
Were previous client goals achieved?	Yes ☐	No ☐
What facilitated goal achievement? What hindered goal achievement?		
Client goals:		

Unlike in the public sector where specialist multidisciplinary teams have a referral process within NHS Trusts, the private sector operates in silos and therefore, ease of referring to community services is reduced. General Practitioners (GP) therefore are responsible for referring on to services. For this reason, I encourage this

assessment to be sent to the GP if additional input from specialist teams such as speech and language, occupational therapy or dietetics is required. This will also ensure that the GP is aware of any changes to a clients' clinical condition.

6.5 Potential of use

I propose implementation of the clinical care pathway at initial assessment to holistically assess patients at baseline to direct appropriate care planning. This would ensure that nutrition and hydration needs are addressed and would provide documented evidence that the care provider is meeting individual needs, in line with CQC regulations and Health and Social Care Act 2009 (Care Quality Commission (CQC 2020).

Early indication of whether input is required from the wider multidisciplinary team to support aspects of care (which will support achieving nutritional optimisation) is a benefit of this tool. Building on this, through identification of nutritional need at the commencement of care planning, CareCo Healthcare and Alpha Food could work collaboratively to train care staff on diet, meal preparation and cooking. This would ensure clients with nutritional need have appropriately trained members of staff allocated to their care team which could then improve nutrition management within this context.

The clinical tool can be printed as a paper copy and stored in the client's daily logs. Before this tool can be used in the future, further research would be required to assess its usability within CareCo Healthcare through a feasibility study. If it were to be implemented, adequate training of care staff and senior staff would be required to standardise method of completion. In line with technological progressions seen in health and social care and the drive for paperless care records, this tool has the potential to be used electronically in the future. This tool could easily be used on a laptop or tablet or, for example an iPad. It is designed with check boxes for ease and timely completion. These present an easily visible indication to severity of nutritional need or need for onward referrals.

Patient access apps and online portals are becoming more popular in community care and self-management and this tool has the future potential to be converted into an app which is patient friendly. In line with

independent living and self-management, it also has the potential to be accessed by patients for them to update their goals or input weekly weights to monitor their progress.

Further research into the potential of this tool is required however the use of Artificial Intelligence with Alexa in Samira's case is inspiring for healthcare innovation. If this tool were electronic and app based, there could be potential for it to sync to Artificial Intelligence such as Alexa and synthesise patient goals. Based on a tailored nutrition and hydration plan of nutritional need, patient preference and their daily routine, voice prompts, reminders or encouragement could then support patients to meet their goals. Alexa could then be used as a hub to recite appropriate recipes within a meal plan set by a dietitian to optimise patient care and ease carer burden.

6.6 Conclusions

The findings which conclude this research are a call for action to raise the profile of nutrition and awareness of malnutrition and optimising nutritional status in the UK, specifically within this high-risk population group. These findings provide insight and understanding of the current context of nutritional practice in people with long term conditions in the homecare setting and highlight unmet needs of both under and overnutrition.

This research has identified nutrition is a low priority in homecare practice, evidenced by its lack of reference in care planning. Evidence presented within this thesis present lack of legislation and guidance to promote nutrition, which is not conducive to driving change. Having presented the human and financial cost associated with both undernutrition and overnutrition with the UK, it is hoped this research is a catalyst for change within legislation in health and social care so that significant improvements required to meet the nutritional need in patients receiving home care are actioned nationwide.

Further research is required to explore nutrition management options in people with long term conditions who receive home care from CareCo Healthcare but there is potential for inspiring innovations in future healthcare with smart technology. Although technological solutions in healthcare innovation provide inspiring scope for

the future, standardised levels of care and practice are required first. This research has identified a need to assess nutrition upon commencing a care plan in order to determine whether there is unmet need, and this should be reviewed as part of standard care. Only through identification and addressing nutritional need can a care provider be certain they are meeting CQC regulations of good quality practice in regard to nutrition and hydration (CQC 2020).

7 Appendices

7.1 Appendix 1

Ethical Approval

Content removed on data protection grounds

7.2 Appendix 2

Gatekeeper Letter

Study Title: An exploration of nutrition in the home care setting: an ethnographic study of care staff and patients with long term conditions

To facilitate my research within CareCo Healthcare I am required to obtain written authorisation to work alongside your patients and employees. The information provided here aims to provide you with an overview of my research study for you to provide informed consent.

Why am I doing this study?

I have been sponsored by CareCo Healthcare and Coventry University to conduct PhD research on the nutritional wellbeing in chronically ill patients in the home-care setting.

We know currently that community dwelling patients with long term conditions are at high risk or already suffer from malnutrition which is augmented by their disease state and co-morbidities. The overall aim of this study is to explore the barriers and facilitators to nutritional wellbeing in this population group. The goal is to explore future or alternate potential solutions which can be implemented to improve nutritional wellbeing and quality of life in this patient group.

What do I need assistance with for this research?

I would like to recruit care staff and clients to participate in this research so that I am able to explore the experiences and opinions of both groups.

Inclusion criteria for participating clients:

Capacity
Diagnosis of a long term condition
Adult (aged 18 years +)
Receive long term home care
Ability to communicate
Able to provide informed consent

Inclusion criteria for staff:

CareCo Healthcare employee
Ability to communicate
Provide home care visits

The gatekeeper role is simply one of distributing information and that interested participants should contact the researcher directly, not the gatekeeper.

What will taking part in the research involve?

I aim to conduct an ethnographic study which involves shadowing care staff on visits to clients. I will be asking care staff questions around nutrition and meal times or nutrition and hydration of their client. I will ask care staff about their experiences and opinions of meal times and food choices of patients to explore their perceptions of barriers and facilitators to nutrition in the home-care setting. I'd like to also explore if care staff have any thoughts on potential solutions to the challenges they face. These will be informal conversations

rather than interviews. Conversations will not be audio taped, instead I will keep fieldnotes of my time with staff which later will be analysed.

I aim to speak with clients about their experience of living with a chronic condition and their knowledge of the impact their condition has on nutrition or hydration requirements. I also aim to explore the attitudes and perceptions of mealtimes and food choice to explore the barriers to good nutritional wellbeing from the patient perspective. Also, if clients have any ideas of solutions to the challenges they experience, I would be keen to discuss this with them. These will also be informal conversations rather than interviews. Conversations will not be audio taped, instead I will keep fieldnotes of my time with clients which later will be analysed.

There are no personal benefits to taking part in this research however those who participate are contributing to healthcare research in the field which may benefit other people in the future.

Who will have access to data from research?

Only myself and your academic supervisor will have access to the data.

Should there be any extenuating circumstances, I may be obliged to break confidentiality and will work with my academic supervisor to ensure I take a safe course of action.

What will happen to the results of the study?

Results from this study will form partial completion of my PhD thesis. This research may also be presented at conferences and form a publication.

Results will be shared with CareCo Healthcare with recommendations for future service improvements based on the findings.

Who should you contact for further information?

Content removed on data protection grounds

Content removed on data protection grounds

7.3 Appendix 2

Perceptions, attitudes and current practices impacting nutritional wellbeing in chronically ill patients receiving long term home healthcare: an ethnographic study

PARTICIPANT INFORMATION SHEET CARE STAFF

You are being invited to take part in research on nutritional wellbeing in chronic disease and home healthcare. Sophie McFarland, Doctoral Research student at Coventry University is leading this research. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to explore and develop understanding of the barriers which limit achieving long term nutritional wellbeing and to understand the lived experience of people with chronic illness who have long term home healthcare needs. This study aims to produce results which can provide suggestions for areas of further research and to act as the basis to build solutions to overcome barriers to good nutrition in this population group.

Why have I been chosen to take part?

You are invited to participate in this study because you are a member of nursing/ care staff at CareCo Healthcare.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping CareCo Healthcare and Coventry University to better understand the barriers to nutritional well being for patients with chronic illness.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure. There are no significant risks associated with participation other than discussing your experiences as a care giver and working with patients.

If you have witnessed poor levels of care and want to discuss this confidentially, you are able to do so. If you feel upset or uncomfortable continuing with the conversation, we can stop at any time.

In the unlikely event that serious unsafe care is witnessed, the researcher has a duty to report this to the relevant authorities.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data set at any time until the data are destroyed on 24/04/2024 or the data are fully anonymised in our records by 05/06/2020. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Research Support Office by email ethics.hls@coventry.ac.uk telephone +44(0)2477658461 so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked several questions regarding caring for patients with a chronic condition in their own homes. In particular this research is interested in your experiences of nutrition in home healthcare in terms of barriers and facilitators. The conversations will take place in a safe environment at a time that is convenient to you. The conversations should take around an hour to complete.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file at Coventry University. All paper records will be stored in a locked filing cabinet in RC115 at Coventry University. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. The lead researcher will take responsibility for data destruction and all collected data will be destroyed on or before 29/04/2024.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint

Content removed on data protection grounds

7.4 Appendix 3

Perceptions, attitudes and current practices impacting nutritional wellbeing in chronically ill patients receiving long term home healthcare: an ethnographic study

PARTICIPANT INFORMATION SHEET FOR SERVICE USERS

You are being invited to take part in research on nutritional wellbeing in chronic disease and home healthcare. Sophie McFarland, Doctoral Research student at Coventry University is leading this research. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study

The purpose of the study is to explore and develop understanding of the barriers which limit achieving long term nutritional wellbeing and to understand the lived experience of people with chronic illness who have long term home healthcare needs. This study aims to produce results which can provide suggestions for areas of further research and to act as the basis to build solutions to overcome barriers to good nutrition in this population group.

Why have I been chosen to take part?

You are invited to participate in this study because you have a diagnosis of a chronic conditions and are receiving home healthcare by CareCo Healthcare.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping CareCo Healthcare and Coventry University to better understand the barriers to nutritional well being for patients with chronic illness.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure. There are no significant risks associated with participation. Discussing your condition or challenges to good health may be stressful for you, however please note that conversations will be confidential and data will be anonymised. If you become upset or uncomfortable continuing with the conversation we can stop at any time.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data set at any time until the data are destroyed on 24/04/2024 or the data are fully anonymised in our records by 05/06/2020. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Research Support Office by email ethics.hls@coventry.ac.uk telephone +44(0)2477658461 so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked several questions regarding your condition, nutrition and health. You will be asked to discuss any barriers or challenges you have experienced regarding nutrition and home care and if there are any solutions you think may help. The conversations will take place in a safe environment at a time that is convenient to you. The conversations should take around an hour to complete.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file at Coventry University. All paper records will be stored in a locked filing cabinet in RC115 at Coventry University. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. The lead researcher will take responsibility for data destruction and all collected data will be destroyed on or before 29/04/2024.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint

Content removed on data protection grounds

7.5 Appendix 4

Participant No.

INFORMED CONSENT FORM FOR STAFF:

Perceptions, attitudes and current practices impacting nutritional wellbeing in chronically ill patients receiving long term home healthcare: an ethnographic study

You are invited to take part in this research study for the purpose of collecting data to explore and develop understanding of the barriers which limit achieving long term nutritional wellbeing and to understand the lived experience of people with chronic illness who have long term home healthcare needs.

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling YES against each of the below statements and then signing and dating the form as participant.

1	**I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions**	**YES**	**NO**
2	**I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office at any time until the date specific in the Participant Information Sheet**	**YES**	**NO**
3	**I have noted down my participant number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study**	**YES**	**NO**
4	**I understand that all the information I provide will be held securely and treated confidentially**	**YES**	**NO**
5	**I understand that if a serious risk of harm has been observed while I have been providing care the researcher is obliged to notify those in authority**	**YES**	**NO**
6	**I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs**	**YES**	**NO**
7	**I agree to take part in the above study**	**YES**	**NO**

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	**Date**	**Signature**

7.6 Appendix 5

Participant No.

INFORMED CONSENT FORM FOR SERVICE USERS:

Perceptions, attitudes and current practices impacting nutritional wellbeing in chronically ill patients receiving long term home healthcare: an ethnographic study

You are invited to take part in this research study for the purpose of collecting data to explore and develop understanding of the barriers which limit achieving long term nutritional wellbeing and to understand the lived experience of people with chronic illness who have long term home healthcare needs.

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling YES against each of the below statements and then signing and dating the form as participant.

1	**I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions**	**YES**	**NO**
2	**I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office at any time until the date specified in the Participant Information Sheet**	**YES**	**NO**
3	**I have noted down my participant number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study**	**YES**	**NO**
4	**I understand that all the information I provide will be held securely and treated confidentially**	**YES**	**NO**
5	**I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs**	**YES**	**NO**
6	**I agree to take part in the above study**	**YES**	**NO**

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	**Date**	**Signature**

7.7 Appendix 6

Topic Guide for Care Staff

Informal conversations will include questions similar to:

“Can you please tell me a bit about mealtimes during client visits”

“How do you perceive the nutritional wellbeing of your clients”

“Have you ever received any training around nutrition and hydration”

“What do you think may be the biggest barriers to providing good nutrition to your clients” “and why”

“is there anything you think may help to overcome this”

These will be informal conversations rather than interviews. Conversations will not be audio taped, instead I will keep fieldnotes of my time with staff which later will be analysed.

7.8 Appendix 7

Topic Guide for Service Users

Informal conversations will include questions similar to:

“Do care staff help you with mealtimes during their visits?”

“Can you please tell me a bit about your mealtimes when you have visits?”

“How do you perceive your nutritional wellbeing?”

“Have you ever received any education or information around your nutrition and hydration needs which relate to your condition?”

“What do you think may be the biggest barriers to achieving good nutrition and hydration?” “and why is that?”

“is there anything you think may help to overcome this?”

“have you ever suffered from falls or pressure wounds?”

These will be informal conversations rather than interviews. Conversations will not be audio taped, instead I will keep fieldnotes of my time with service users which later will be analysed.

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